School Advisory Toolkit for Families

This guide offers collaborative methods for educators and parents of children with diabetes to ensure that every child enjoys the best possible school experience.
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About the Author and the Goal of this Guide

Harold Wolff is the parent of two sons: Michael, who was diagnosed with type 1 diabetes when he was 3½ years old, and Brian, who was diagnosed when he was 26. Both sons are leading active and healthy adult lives. Harold taught students in grades four through 12 for the first half of his educational career. For the last 16 years of his career, he was the principal of a middle school (grades six through eight) with 1,500 students.

These experiences give Wolff a unique perspective on the issues of school and child/parent relationships as it relates to diabetes management. Although there is currently information available on how to deal with school personnel, this Guide provides a balanced approach to how parents of a child with diabetes and the school can work together to provide a safe, caring, and positive learning environment for the child/student. The goal is for both the parent's and school's points of view to be communicated, heard, and understood and to encourage a cooperative effort to provide the very best school experience for the child with diabetes.

Manual Overview

As a parent you know that your child spends most of his day in the school setting; in the care of teachers, nurses, and other school personnel. Most parents are comfortable with this environment, as most students’ healthcare needs consist of Band-aids for the occasional scrape, oral medications, and the occasional ice pack. As the parent of a child with diabetes, however, you know that the day-to-day disease management is intensive and that the school must play an important role in this care.

The Juvenile Diabetes Research Foundation (JDRF) understands the importance of your child's care in the school setting. After receiving several requests from parents for help in their children's schools, JDRF conducted an extensive research report. This report led us to develop this toolkit in conjunction with Harold Wolff and with contributions from Tamara Burns, JDRF Triangle/Eastern NC Chapter volunteer and mother to a child with type 1 diabetes. We thank Tamara for her contributions to the original School Advisory Toolkit, as well as Lynn Langbein – JDRF Capitol Chapter and mother to a child with type 1 diabetes – for her contributions to Appendix I, and Nanette Corriere – JDRF Westchester County Chapter and mother to a child with type 1 diabetes – for her contributions to Appendix II. We hope this guide will equip you for working with your child's school to ensure that proper diabetes care is provided.

For further information or support with diabetes in the school setting please reach out to your local chapter. You can find the chapter closest to you by going to www.jdrf.org and selecting the Locations tab near the top of the homepage.

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Under no circumstances will JDRF be liable for any direct, indirect, special or other consequential damages arising out of any use of this manual.
Communicating with Schools

- A message to school staff
- A message to parents
- The right approach – the cooperative and respectful way
- The wrong approach – the adversarial way
- How to handle difficult situations that may arise
A Message to School Staff

Realistic Expectations Parents Have of School Personnel
(parents should read this, too)

You have a child with diabetes enrolled in your school and you want him/her to have the very best school experience possible. You have every reason to expect that the child’s parents will work with you in a friendly and cooperative manner and provide as much support and assistance as they are able. You also have every reason to expect that the child’s parents will appreciate your efforts to provide a safe and caring learning environment and understand the overwhelming responsibilities that teachers and the school hold. If you make a good faith effort to provide for the child with diabetes’ needs, the parents should understand if, occasionally, you ask for their time, help, and support.

Working with parents in a cooperative, friendly, and mutually respectful manner requires that you understand the parent point of view. Parents obviously need to take care of their children, BUT the parents can’t do it all. Parents should do their part in providing information, snacks, supplies, emergency directions, etc., but the school needs to understand that even the best and most caring parents can’t anticipate all of the school needs of their children. Parents often have jobs, family responsibilities, and stresses that can sometimes be overwhelming.

Now, add to the mix a child with diabetes, and suddenly parents are confronted with the highly emotional task of raising a child with a serious and potentially life-threatening chronic disease. Feelings of guilt, anxiety, and fear are only the tip of the iceberg for these parents. Sleepless nights become a regular occurrence; parents sometimes stay up all night worrying and checking blood sugars to make sure their child doesn’t have a serious hypoglycemic reaction. They also must do the following:

- Learn to count carbohydrates and sometimes change their family’s diet
- Learn about long and short acting insulin
- Learn to give shots or use an insulin pump
- Learn to check their child’s blood sugar and interpret the results
- Understand how exercise, illness, and stress affect blood sugars
- Mediate rivalries and feelings of jealousy between their children
- Build the self-esteem and understand the range of emotions of a child who suddenly is very different from others
- Combat ignorance and prejudice on a daily basis concerning their child’s diabetes

…all this while trying to remain the calm, dependable mother or father they have always been.

School Personnel – the parents would like you to know that they care about their child and want to do what’s best for him, but they can’t be everywhere all the time and can’t do it all. They need your cooperation, assistance, and understanding of what they are dealing with on a daily basis.
A Message to Parents

Realistic Expectations You Have of School Personnel
(school staff should read this, too)

Of course, you want the very best school experience possible for your child. You have every reason to expect that your child will be welcomed at school and that school personnel will happily provide a caring and safe place in which your child learns and grows to the best of his/her ability. It is true that your child’s school has legal obligations that mandate certain kinds of services for your child, and if the school does not partner with you in an appropriate manner, pursuing legal means (e.g., a 504 Plan) may be necessary. But please be assured that your child will thrive better if he/she observes you and the school working in a cooperative, friendly, and mutually respectful manner. This requires that you understand the school’s point of view in addition to your own.

The school has legal and moral obligations to your child, but the school can’t do it all. The school staff should make a good faith effort to provide for your child with type 1 diabetes, but keep in mind that they are only human. Even the best and most caring teachers and staff can’t magically make a nurse appear if one is not available. School personnel are incredibly busy with endless responsibilities. What goes on in a school and in a teacher’s classroom on a daily basis is mind-boggling. A teacher is not only responsible for the medical needs of your child but of other children as well. A teacher is responsible for creating a positive learning environment, planning lessons, delivering effective and interesting instruction, taking attendance, planning field trips, participating in other school activities (coaching, sponsoring clubs, supervising evening activities, etc.), continuing his/her own education, grading papers, communicating with parents and special education teachers, attending faculty meetings, filling out paperwork, meeting State and Federal mandates, and dealing with the social, emotional, physical and intellectual needs of their students.

While instructing, teachers are constantly:

- observing student reactions and gauging understanding of what is being taught
- monitoring and dealing with student behavior
- adjusting instruction for students’ individual needs and styles of learning
- responding to instructions or interruptions from the office

...and all this while leaving no child behind. The nurse, office staff, and administrators are also working hard at their own jobs and are just as busy as the teachers.

Parents — school personnel would like you to know that they care about your child and want to do what’s best for her, but they can’t be everywhere all the time and can’t do it all. They need your cooperation and understanding of how much they do.

The Right Approach — The Cooperative and Respectful Way

It’s 4 to 5 weeks before school starts. A parent calls the school and communicates to the secretary that her daughter has just been diagnosed with type 1 diabetes. The parent requests a meeting with the principal (and if possible, the nurse and teacher) when it is convenient. The parent acknowledges that this is a busy time of year for school staff, but explains that it is important that they meet before the start of the school year to work together to come up with procedures to ensure the safety of her daughter.

At the scheduled meeting: The parent acknowledges that the school is a wonderful place, that everyone is busy, and that she will be adding responsibilities. She comments on how much she appreciates what all of the people in the room will be doing for her daughter, as their time is valuable. She expresses her hope that together, she and the school staff will be able to create a plan to provide the best and safest learning environment possible for everyone.

The parent also communicates that she has a full-time job but knows that she, on occasion, will have to help out (e.g., chaperone a field trip or perhaps come to the school to give blood tests and/or shots). The parent provides information to help the school gain an understanding of type 1 diabetes and how to care for a child with diabetes at school. The parent provides information about when the daughter will need lunch, physical education, and snacks. If a physical education class or lunch for the daughter’s grade level is not available during these times, the parent understands and asks if they could work together to provide the best schedule that is possible.
The principal, teacher, nurse, and parent all follow through on their agreed upon roles – and not only does the daughter learn and grow in a most positive school environment, she also learns how to work cooperatively and respectfully with others.

The Wrong Approach – The Adversarial Way

It’s registration time at the beginning of the school year. The school is crawling with students and parents and the school administrators, teachers, and secretaries are quite busy. A parent brings her daughter with diabetes into the office, states that her daughter is diabetic, and demands an immediate meeting with the principal, nurse, and teacher.

Somehow, the principal, nurse, and teacher manage to put aside their other pressing duties on this busy Registration Day and meet with the parent and child. The parent is emotional and demands that the school take care of her daughter – letting the daughter come to the nurse’s office whenever she wishes and eat snacks whenever she wishes. The parent also tells the school that she “knows her rights” and that the school must provide a full-time nurse to take care of her daughter and that if the nurse is out, the school should hire a substitute nurse. She also says flat-out that she is a busy mother who won’t be available to go on any field trips or help out in any way.

The principal, nurse, and teacher have an immediate reaction. They are already feeling overwhelmed with all that they have to do – to hear that this student will need to be closely monitored and that low blood sugar is a life-threatening event is dire and frightening news. The teacher feels stress and even fear and wonders if she is capable of handling an emergency of this nature. How will she remember all that she’s supposed to do for this child?

The “fight-or-flight” response kicks in and the school staff become defensive. The principal tells the parent that her child needs to be home-schooled and that her child can’t attend this school unless she is totally independent and can take care of herself. Or the nurse says that she is too busy; the parent will have to come in four times per day to test the child and give her any necessary insulin shots.

The parent again threatens that she knows her rights and she’ll get a lawyer to force the school to cooperate with a 504 Plan. A long-term adversarial relationship is begun.

How to Handle Difficult Situations That May Arise

Unexpected situations may arise during your child’s school years. Many of these situations may take you by surprise. Teachers, administration, rules, or other things may change suddenly or over time. These changes may cause you to jump to conclusions, but try not to react before you have all of the information. Some key things to remember when facing an unexpected challenge are:

- Remain calm
- Take a deep breath
- Gather all the facts
- Offer another way to handle things (seek win-win solutions)
- Seek support (e.g., local JDRF Chapter)
 Diabetes Basics

- What is type 1 diabetes?
- What is type 2 diabetes?
- Type 1 diabetes facts
- Diabetes control & management
- High blood sugar – definition, symptoms
- What to do about high blood sugar levels
- Low blood sugar – definition, symptoms
- What to do about low blood sugar levels
- What is glucagon?
- Checking blood sugar levels
- Insulin delivery methods
- Effects of exercise, illness, stress, and growth on blood sugar levels
**What is Type 1 Diabetes?**
*(a simplified explanation)*

Type 1 diabetes often develops in children, adolescents, and young adults, so it's sometimes called “juvenile diabetes.” Diabetes is not contagious. You cannot catch diabetes from someone who has it. Researchers continue to study how and why diabetes occurs in certain children and families. Although diabetes cannot be cured, it can be controlled.

**About Blood Sugar Levels**

A healthy pancreas produces insulin, a hormone that the body uses to change glucose in the blood into energy. Glucose in the blood comes from the food and drink a person consumes. A person with type 1 diabetes doesn’t produce any insulin. Without insulin, the glucose builds up in the blood, causing high blood sugar, or hyperglycemia. Blood sugar levels that are too high and untreated for long periods of time can lead to ketoacidosis, a very serious condition. Very high blood sugars for an extended period of time can eventually lead to coma and death.

In people without diabetes, the pancreas maintains a “perfect balance” between food intake and insulin. When a person eats, the pancreas puts out the exact amount of insulin needed to turn the glucose into energy. If the person eats a lot, the pancreas puts out a lot of insulin. If the person eats just a little, the pancreas puts out just a little insulin.

**Insulin Needs**

Since people with type 1 diabetes can’t produce their own insulin, they must put insulin into the blood stream through injections or an insulin pump. If people with type 1 diabetes inject too much insulin (or eat too little) they may have a hypoglycemic reaction. Hypoglycemia (low blood sugar) is the most common problem in children with diabetes. It can be very serious and requires immediate action.

People with type 1 diabetes often struggle to determine how much insulin to inject. In a simple and perfect world, this question would have an easy answer (e.g. always eat a certain amount of food and inject a certain amount of insulin). However, in reality there is no way to know how much insulin to inject with 100% accuracy. Many factors influence how much insulin people need to get to the desired “perfect balance” of glucose and insulin. These factors include foods with different absorption rates as well as the effects of stress, illness, and exercise. Also, as children grow, their insulin needs change.

Since determining how much insulin the body needs to “balance” the amount of glucose is really a best guess, sometimes the guess is inaccurate and high or low blood sugar results.

**Risk of Complications**

High blood sugar levels over a number of years can cause serious damage to the body’s organ systems. This damage may cause complications affecting the heart, nerves, kidneys, eyes, and other parts of the body. A number of studies, however, have proven that careful monitoring and control of blood sugar levels greatly reduces the threat of these complications. Researchers are also making progress at developing new treatments and technologies to help people with diabetes stay healthy. It’s important to remember that people with diabetes can lead active and productive lives, just like anyone else.

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**Diabetes is not contagious.** You cannot catch diabetes from someone who has it. Researchers continue to study how and why diabetes occurs in certain children and families. Although diabetes cannot be cured, it can be controlled.

**What is Type 2 Diabetes?**
*(a simplified explanation)*

People with type 2 diabetes produce some of their own insulin, but the insulin is either insufficient in quantity or ineffective in its ability to stabilize blood sugar levels. Ineffective action of insulin is called insulin “resistance.” Many factors can cause insulin resistance; a major cause is known to be obesity. People with type 2 diabetes can sometimes manage their disease with diet and exercise. Some individuals with type 2 can take an oral medication that improves the effectiveness of the insulin, while other type 2’s need to inject additional insulin.

Most school age children with diabetes have type 1. Unfortunately, however, as more and more of our nation’s children become overweight and sedentary, type 2 diabetes is occurring more frequently in school age children.
Type 1 Diabetes Facts

Type 1 diabetes is an autoimmune disease in which the body’s immune system attacks and destroys the insulin-producing cells of the pancreas. While its causes are not yet entirely understood, scientists believe that both genetic factors and environmental triggers are involved.

Affects Children and Adults

Type 1 diabetes usually strikes children, adolescents, and young adults, but it can be diagnosed in adults as well. It comes on suddenly, causes dependence on injected or pumped insulin for life, and carries the constant threat of devastating complications.

Needs Constant Attention

To stay alive, people with type 1 diabetes must take multiple insulin injections daily or continually infuse insulin through a pump. They must also test their blood sugar by pricking their fingers for blood six or more times a day. While trying to balance insulin doses with their food intake and daily activities, people with this form of diabetes still must always be prepared for serious hypoglycemic (low blood sugar) and hyperglycemic (high blood sugar) reactions, both of which can be life-limiting and life-threatening.

Not Cured by Insulin

While insulin injections or infusions allow a person with type 1 to stay alive, they do not cure diabetes, nor do they necessarily prevent the possibility of the disease’s devastating effects, which may include: kidney failure, blindness, nerve damage, amputations, heart attack, stroke, and pregnancy complications.

Difficult to Manage

Despite paying rigorous attention to maintaining a meal plan and exercise regimen and always injecting the proper amount of insulin, people with type 1 diabetes face many other factors that can adversely affect efforts to tightly control blood sugar levels. These factors include stress, hormonal changes, periods of growth, physical activity, medications, illness/infection, and fatigue.

Statistics

- As many as three million Americans may have type 1 diabetes.
- Each year, more than 15,000 children - 40 per day - are diagnosed with type 1 diabetes in the U.S.

Warning Signs

Warning signs of type 1 diabetes may occur suddenly and can include extreme thirst, frequent urination, drowsiness or lethargy, increased appetite, sudden weight loss, sudden vision changes, sugar in the urine, fruity odor on the breath, heavy or labored breathing, and stupor or unconsciousness.

What is it Like to Have Type 1 Diabetes?

Ask people who have type 1 diabetes, and they will tell you: It’s difficult. It’s upsetting. It’s life-threatening. It never goes away.

“Both children and adults like me who live with type 1 diabetes need to be mathematicians, physicians, personal trainers, and dieticians all rolled into one. We need to be constantly factoring and adjusting, making frequent finger sticks to check blood sugars, and giving ourselves multiple daily insulin injections just to stay alive.”

- JDRF International Chairman Mary Tyler Moore

“This disease controls our lives with all the pricking of the fingers, shots, high and low blood sugars; it’s like being on a seesaw. Without a cure, we will be stuck on this seesaw ‘til the day we die.”

- Tre, 12, Michigan

“I never realized how much of my day would be spent dealing with this disease and all of its challenges.”

- Patrick, 13, Connecticut

“A cure would give us freedom to carry on a normal life without taking a break to check our blood or have a snack.”

- Asa, 16, North Carolina
Diabetes Control & Management

Treating Type 1 Diabetes

The main goals of treating children with type 1 diabetes are:

• Maintaining normal growth and development
• Keeping blood sugar levels within a target range (not too high, not too low)
• Promoting healthy emotional well-being

The key to good diabetes control is a careful balance between food, exercise, and insulin. It’s a juggling act to keep blood glucose levels within the target range. Therefore, children with type 1 diabetes must stick to their scheduled blood check, insulin injection, and snack times. Even small changes from a child’s diabetes care plan schedule can cause blood glucose levels to rise or fall.

Remember: Food raises blood glucose levels, while insulin and exercise lower them. A good type 1 diabetes treatment plan includes:

• Eating reasonably, consistently, and on schedule
• Testing blood sugar levels regularly
• Adjusting insulin based on blood sugar levels and activities
• Exercising regularly

High Blood Sugar – Definition, Symptoms

High blood sugar, or hyperglycemia, occurs when the body has too much food or glucose, or too little insulin. The following are all potential reasons that a person with type 1 diabetes might have high blood sugar:

• Not enough insulin taken
• Eating more than usual
• Eating earlier than usual
• Eating food with higher glucose content without injecting extra insulin
• Injecting insulin at a site on the body where the absorption rate is slower or at a site that is over-used
• Missing or skipping an insulin dose
• A clog in insulin pump tubing
• Less exercise than normal

• Stress
• Illness or injury
• Other hormones
• Medications

High blood sugar generally does not immediately put the person with type 1 diabetes in danger. However, high blood sugar levels over long periods of time can lead to serious complications. The complications for diabetes primarily involve small blood vessels (microvascular) or large blood vessels (macrovascular). Microvascular disease includes eye disease, kidney disease, and nerve disease. Macrovascular disease includes heart disease and stroke. Disease leading to amputation usually involves both loss of sensation (nerve disease) and large vessel disease.

Very high blood sugar levels can lead to diabetic ketoacidosis (DKA), or a “diabetic coma.” DKA occurs when the cells can’t get the energy they need from glucose, and the body begins to burn fat and body tissue for energy. This causes the release of byproducts called ketones, which are dangerous when released at high levels. Ketones become like poison to the body and are passed in the urine as they build up in the blood.

A person with type 1 diabetes and high blood sugar may exhibit one or more of the following symptoms:

• Thirst (dehydration)
• Frequent urination
• Blurry vision
• Stomach pain
• Increased hunger
• Nausea
• Drowsiness, lethargy, exhaustion
• Confusion
• Sweating
• Fruity, sweet, or wine-like odor on breath
• Vomiting
• Inability to concentrate
• Weight loss (a longer term symptom) that eventually leads to coma
What to do About High Blood Sugar Levels

The following recommendations are general treatments for high blood sugar. Specific actions — such as giving additional insulin — should be determined by the caregiver responsible for type 1 diabetes management, in consultation with the health care provider prescribing the diabetes medicines.

1. If blood test results are slightly above normal*:
   - Continue regular activity
   - Drink water or sugar-free drinks
   - Monitor blood sugar levels by checking regularly
   - Chart blood glucose test results

2. If blood test results are moderately high:
   - Don’t engage in strenuous exercise
   - Drink water or sugar-free drinks
   - Inject additional insulin if instructed by physician or parents
   - Monitor blood sugar levels by checking regularly
   - Chart blood glucose test results

3. If blood test results are very high:
   - Don’t engage in strenuous exercise
   - Drink water or sugar-free drinks
   - Inject additional insulin if instructed by parents or physician
   - Test ketone levels if advised by parents or physician. If high, contact parent or physician immediately
   - Monitor blood sugar levels by checking regularly
   - Chart blood glucose test results

* Please discuss with your physician what would be considered a normal blood sugar range for your child.

Low Blood Sugar – Definition, Symptoms

Low blood sugar (hypoglycemia) is the most common and most dangerous condition for many people with type 1 diabetes. Very low blood sugar may lead to insulin shock, which can be life threatening if not promptly treated. Low blood sugar occurs when the body has too little food/glucose or too much insulin. The following are all potential reasons that a person with diabetes might have low blood sugar:

- Too much insulin taken
- Eating less than usual
- Eating later than usual
- Insulin was injected at a site on the body where the absorption rate is faster than usual
- Injecting extra insulin after forgetting about a previous dose
- More exercise than normal
- Illness or injury
- Other hormones
- Medication interaction

The following is a list of general symptoms that indicate low blood sugar (the person with type 1 diabetes may exhibit one or more of these):

- Dizziness
- Nervousness
- Personality change/irrational behavior
- Blurry vision
- Shakiness
- Nausea
- Crying
- Sluggishness
- Sweating
- Poor coordination
- Hunger
• Lightheadedness
• Irritability
• Drowsiness
• Erratic response to questions
• Inability to concentrate

Severe symptoms (symptoms as listed above, plus):
• Convulsions
• Unconsciousness

What to do About Low Blood Sugar Levels

A blood glucose meter reading below the target range specified by the physician indicates low blood sugar. The following are general treatments for low blood sugar. The physician and parents (for a child) should determine what course to follow. Please note that people with type 1 diabetes have symptoms of low blood sugar at various readings. Some people with type 1 diabetes feel perfectly fine at readings below 70. Others begin to show low blood sugar symptoms at readings somewhat above 70.

1. If blood sugar levels are slightly low and the person is alert and lucid, he or she should:
   • Not exercise.
   • Eat. After eating, check blood sugar level again to make sure it is within the target range. The person may require another snack later in the day.
   • Continue to check blood sugar levels regularly.

2. If blood sugar levels are low and individual is showing signs of low blood sugar but is still able to eat,
   • He or she should immediately eat or drink a fast-acting source of glucose (i.e., juice, glucose gel, or tablets). He or she may need to eat more food after that (i.e., crackers or other complex carbohydrate).
   • Continue to check blood sugar levels regularly.

3. If blood sugar levels are low and individual is showing signs of low blood sugar and is unconscious, convulsing, and/or unable to swallow:
   • Remain calm
   • DO NOT administer food or drink to someone who has an altered mental status or is unconscious, as it may obstruct the airway
   • Call 911
   • Administer emergency glucagon shot. It MAY take up to 10 minutes for the shot to cause the blood sugar to rise, and for the person to respond. The shot can cause some people to vomit, so make sure to keep the person positioned on his or her side to prevent choking in case vomiting occurs
   • Continue to check blood sugar levels regularly
   • Give additional food (i.e., crackers or other complex carbohydrate) when able to eat, if needed, in order to keep blood sugar levels in target range
What is Glucagon?

People with type 1 diabetes who experience severe low blood sugar emergencies may require glucagon. Glucagon raises the blood sugar when a person with type 1 diabetes is unable to swallow liquid or food because of severe sleepiness, unconsciousness, or seizure activity. Glucagon, like insulin, must be injected with a syringe into the skin. It is a hormone that helps the liver to release stored glucose in order to raise blood sugar levels. If there is not stored glucose in the liver, glucagon will not work.

Glucagon Kits

Glucagon is packaged in a kit with a vial of powder containing the medicine and a syringe filled with liquid to mix with the medicine. Directions for mixing and injecting the medicine are in the package. Read the directions carefully and ask your healthcare provider for more explanation, if necessary.

Do not mix glucagon after the expiration date printed on the kit and on the vial. Check the date regularly and replace the medicine before it expires. After mixing glucagon, discard any unused portion, regardless of the expiration date.

Tip: Expired glucagon kits may be a good way to “practice” mixing the powder and liquid; after practicing dispose of the expired glucagon.

Checking Blood Sugar Levels

People with type 1 diabetes must check their blood sugar (glucose) levels throughout the day using a blood glucose meter. The meter tells them how much glucose is in their blood at that particular moment. Based upon the reading, they take insulin, eat, or modify activity to keep blood sugars within their target range. Regularly checking blood sugar levels is an essential part of type 1 diabetes care.

Methods for Checking Blood Sugar Levels

Checking, or testing, involves taking a drop of blood, usually from the fingertip, and placing it on a special test strip in a glucose meter. Blood glucose meters are easy to use, and even young children often learn quickly how to do their own blood glucose checks. In order to properly manage their diabetes, individuals with type 1 diabetes check their blood sugar levels several times per day. For example, they may test before eating lunch and before strenuous exercise.

Blood sugar levels are measured in milligrams per deciliter (mg/dL). A normal blood sugar level is between 70 and 120 mg/dL. Keeping blood sugar levels within this range may be difficult in children with diabetes. Therefore, an individual’s doctor may adjust the target range (for example, 80-180 mg/dL).

However, people with diabetes can’t always maintain blood sugar levels within the target range, no matter how hard they try. A person’s varying schedules and eating habits, as well as the physical changes that occur as they grow, can send blood sugar levels out of range for no apparent reason. A person with type 1 diabetes should never be made to feel that it is their fault if their blood sugar levels are out of range.

The Latest Technology in Blood Glucose Checking

As of 2006, a new device called a continuous glucose monitoring (CGM) system is available to test blood sugar. It works much like an insulin pump and constantly displays an individual’s blood glucose level on a screen. This system still requires a few finger pokes during the day but greatly reduces the number of meter tests. The CGM attaches to the body like an insulin pump, and the site must be changed at least every 3 to 5 days.

Insulin Delivery Methods

Syringes, insulin pens, and insulin pumps all serve the same purpose: to deliver insulin to a person with type 1 diabetes, who does not produce insulin on her own.

Insulin Injections

To stay alive, people with type 1 diabetes must inject insulin many times a day. The exact number of injections varies from person to person. Insulin injections typically occur at regularly scheduled times during the day. Syringes or insulin pens are both used for injections, but both essentially do the same thing. Some people find the pen to be more convenient when they only need a single kind of insulin. Some children also find the pen needles more comfortable than the syringe needles. The age at which children are able to administer their own injections varies. After working through the initial trauma of being diagnosed with type 1 diabetes, however, most children eventually inject their own insulin.
**Insulin Pumps**

An alternative to insulin injections is the insulin pump. The pump is a computerized device, about the size of a beeper or pager, often worn on a belt or in a pocket. The pump delivers a continuous low (basal) dose of insulin through a cannula (a flexible plastic tube), which attaches to the body through a small needle inserted into the skin. The cannula is taped in place and the needle is removed. Common insertion sites on the body include the thighs, buttocks, upper arms, stomach and other areas with fatty tissue.

When a person wearing a pump eats, he/she pushes a button on the pump to deliver an extra amount of insulin called a bolus.

The advantages of the pump include:
- Greater flexibility with meals, exercise, and daily schedule
- Improved physical and psychological well-being
- Smoother control of blood glucose levels

The disadvantages of the pump include:
- Risk of infection
- More frequent hypoglycemia (low blood sugars)
- Ketosis and ketoacidosis (risk of very high blood sugars)
- Constant physical reminder of diabetes

A person with type 1 diabetes who uses an insulin pump may need to test her blood sugar more frequently.

**Personal Choice**

Choosing an insulin delivery method is a personal decision for a person with type 1 diabetes, made by the individual, family (if a child), and medical provider. The same method may not be the right choice for everyone.

**Effects of Exercise, Illness, Stress, and Growth on Blood Sugar Levels**

Exercise, illness, stress, and growth all affect blood sugar levels in a child with type 1 diabetes.

Exercise makes insulin work more effectively because it takes less insulin to balance the carbohydrates consumed. Therefore, children who begin to exercise more may find that taking their typical doses of insulin before eating a typical amount of food may result in lower blood sugar levels. (Note: Every child is unique and several factors affect blood sugar levels, so exercise will not always result in lower blood sugar levels.)

At school, this situation occurs in physical education classes, where activities and intensity levels vary daily. Sometimes students are learning how to play a game, and the physical intensity level is low. Other days, students spend more time playing games, running, or doing other strenuous activities. On days like this, children with diabetes should be more aware of how they are feeling and have extra snacks and insulin on hand. Physical education teachers should monitor the student more closely before and during the activity.

A child may also be more active during recess and field trips. Older children with diabetes who participate in a sport need to plan for this additional activity. They may reduce insulin intake or eat extra food before the activity begins.

Illness and stress, on the other hand, often cause blood sugar levels to rise. A child who doesn't feel well may have trouble performing in class. She may have difficulty concentrating, for example. In such cases, the teacher can help reduce some of the stress by providing extra time for students with type 1 diabetes to complete tests or other work. Teachers may also need to be more patient as the student works to grasp new ideas and concepts.

Sometimes a child will achieve (at least for a short time) the “perfect balance” of insulin and food intake. Life can be rewarding and even close to normal for several months or longer. Then something as simple as a growth spurt could suddenly throw everything off. Early adolescence is an especially difficult time: the body grows, and hormones turn boys and girls into men and women. Children may have more issues with blood sugar at this time and require more help emotionally and physically, both at home and at school.
Parent/School Partnership

• An adult and a backup
• Recommended parent responsibilities
• Recommended administrator responsibilities
• Recommended school nurse responsibilities
• Recommended student responsibilities

• Recommended teacher/staff member responsibilities
• Other staff responsibilities (i.e. bus driver, PE teacher, food service coordinator)
• The most important rules

*See Disclaimer on page 1 of this manual.
Parent/School Partnership

It is essential to establish a partnership with your child’s school in order to create a supportive environment in which he can learn and thrive. The parents’, students’, and school’s needs must be mutually communicated, heard, and understood.

From the first day your child returns to school post-diagnosis you should make every attempt to establish a positive partnership with the school. Be sure on the first day to explain the vast differences between type 1 and 2 diabetes to your child’s teacher. While most people know of diabetes, much of their knowledge is usually about type 2. The Diabetes Basics section of this manual is designed to help with the education of teachers and even school nurses about type 1. The school nurse may or may not have had previous experience with other children with type 1 diabetes; regardless, it is important for the school nurse to understand that each person’s experience with the disease is different.

In cases where there is no school nurse on site, another adult in the school — usually a teacher or administrator — should be designated as the “go to person” for your child. That adult needs to learn all he or she can about your child’s diabetes management routine in order to support your child throughout the school day.

A key part of a positive parent/school partnership is a clear understanding of who will be responsible for each task. In this section you will see a suggested list of responsibilities for all parties involved. You should feel free to tailor this list to your personal situation.

Here are a few more ideas for nurturing the partnership with your child’s school:

- Keep the lines of communication open and show that you appreciate the partnership
- E-mail care team members after first meetings thanking them for attending, offering them your complete contact information and any useful local information. Let them know they can contact you with any questions at any time
- When and if appropriate, inform them of the presence of JDRF in your community and the work they are doing to find a cure
- Check in with the teacher about your child’s diabetes regimen regularly, and separately from academic conferences
- Check in regularly with the school nurse as she may be aware of other concerns
- Check in about replenishing supplies as necessary
- From time to time, eat lunch with your child at school to meet the lunchroom staff and monitors
- After each grading period teachers may change or unused information may be “compartmentalized;” consider holding another informational or training session with new staff
- Send a holiday greeting thanking administration and all care team members for their participation and constant care

An Adult & a Backup

Ideally, at least one adult and one “backup” should be trained to check your child’s blood sugar and recognize and treat low blood sugar (hypoglycemia) and high blood sugar (hyperglycemia) levels. These adults should also know when and how to check for ketones and what to do if the ketone level is abnormal. If the child is mature enough to treat himself/herself, he/she should be allowed to do so — but the student should remain under the supervision of an adult at all times during a hypoglycemic reaction and should not be allowed to walk alone to another part of the school to test blood glucose or get treatment.

If the parent or child requests it, the school should provide a location in which the child can check her blood glucose or take insulin privately (but still with adult supervision, if needed). The two adults should also be trained to give a glucagon injection in case of emergency. The responsibility for glucagon administration by school staff is similar to school staff being prepared to give a shot (epi-pen or similar) to a child in the school who is allergic to bees.
Further responsibilities of adult caregivers should include:

- Knowing the student's meal plan and working with the parent to accommodate special events/meals if possible
- Allowing the student to see the school nurse or other school medical personnel whenever needed
- Allowing the student to eat a snack anywhere as needed, and to use the restroom and drink water at any time
- Allowing the student to miss school for doctor’s appointments to monitor diabetes without incurring negative consequences
- Providing a safe and secure location for storage of insulin and glucagon, and allowing the student immediate access to diabetes supplies at any time
- Ensuring the student’s full participation in all sports, extracurricular activities, and field trips, with any necessary supervision provided
- Providing aids to help the student academically, if needed. Examples of situations in which this might be necessary include making up for class time missed due to diabetes care or academic problems that can be traced to frequent hypoglycemia or hyperglycemia

Recommended Parent Responsibilities

- Inform the school/administrator that your child has type 1 diabetes
- Provide the information needed for training of school staff (samples provided in Diabetes Basics and Educate the Educator sections of this guide)
- Work with the administrator and/or school nurse to provide this training
- Understand teacher and school personnel schedules and that all staff members involved with your child may not be able to attend the same training time, so training may have to be given more than once
- Work with the principal or building administrator to identify school staff (hopefully including main academic teacher) for more in-depth training
- Provide specific information about your child (include your child's picture on forms)
- Work with school staff to determine when and where blood testing is to take place
- Clearly communicate (verbally and in writing) your permission for school staff to call 911 whenever they deem it necessary and to administer glucagon – no questions asked
- Clearly communicate that the school has your permission to share the needed medical information about your child with everyone who needs to know
- Provide multiple emergency contact people and phone numbers including your physician
- Be sure to communicate with school staff any changes that occur concerning your child and his/her diabetes management
- Provide all the necessary equipment, supplies, snacks, and emergency items needed. You will also want to set up a system with teachers and other staff to alert you when supplies or snacks are getting low. A school kit might include:
  - Vials of your child’s insulin – clearly labeled with child’s name
  - Syringes
  - A second glucose meter to keep at school – including batteries and test strips
  - One or more glucagon kits (renew each year as they expire)
  - Glucose tablets, juice boxes, or another form of fast acting sugar
  - Cake icing or glucose gel
  - Snacks containing protein, such as peanut butter crackers
  - A mini carb counting guide (found at most bookstores)
- Work with the principal to develop a process to cooperatively and amicably address disagreements or issues if and when they arise
- Encourage your child to wear a medical alert ID
• Make sure that your child understands that he/she is not to take unfair advantage of modifications or accommodations provided (e.g., trying to get out of physical education activities when she feels just fine)

• Accept the fact that it may be your child who is resistant to the assistance or procedure that school personnel are trying to provide. Don't blame, but work with school personnel to resolve these issues

• Provide an emergency/disaster kit for any situation which might require your child to stay at school for a longer than expected period of time

• Work with appropriate school personnel to develop a 504 Plan. Remember that a 504 Plan provides reasonable accommodations for your child. Also remember that the goal is to provide accommodations that your child really needs or would need in a special circumstance (e.g., standardized testing)

• Communicate with and train staff members new to your child during the school year (e.g., after-school club sponsor if your child joins a club after the school year begins)

• When appropriate, include your child in all discussions and decisions made about him/her

• Clearly state to your child who should be contacted at school if she feels ill

• Promote, encourage, and teach your child the skills to become more and more independent in her diabetes management and care. Discuss the level of independence of your child for blood testing and shot/insulin pump management (depends on age level/maturity of child) with school staff

• If the school and school personnel are making a good faith effort to do all that is possible for your child, help out as much as you can when the school requests your assistance. (e.g., legally, the school may be responsible for providing a nurse to provide for your child's needs. But if the school nurse is ill and school personnel are unsuccessful in arranging for a substitute, thank them for trying and then give up your day to go to school and provide services for your child.)

• Help out at some after-school or extracurricular events when your child is participating. These are especially difficult times for schools to provide the appropriate trained staff members

Recommended Administrator Responsibilities

• Become knowledgeable about diabetes, especially the differences between type 1 and 2

• Meet with the parent/student at the beginning of the year or when the child is diagnosed to set up the year-long plan for management and care

• Identify and arrange for training of appropriate school staff. Besides the more obvious classroom teachers, don't forget the band teacher, coach, librarian, any special education teachers, bus driver, substitute bus driver, lunchroom supervisors, hall monitors, etc.

• Identify school staff (including main academic teacher) for more in-depth training. These staff members are then available to provide an extra level of care when the nurse is not available

• Work with parent and school staff to determine where blood testing is to take place

• Provide leadership to foster and support a positive learning environment for the student; act as an advocate for the student; clearly communicate to teachers and other staff members in contact with the student your expectations for them to cheerfully follow through on the modifications and accommodations set up for the student.

• Set up an “emergency” system that clearly communicates to the student what to do if an adult in the building refuses to allow the student to do what is needed. Make sure that the student understands that there will be no disciplinary action taken against the student for following through on the agreed upon actions (e.g., leaving class to come to the nurse’s office even if a substitute teacher says that the student cannot leave class). Remind the student not to take advantage of these “special” rules

• Work with the parent to develop a process to cooperatively and amicably address disagreements or issues if and when they arise
• Work with the parent to address the emotional issues involving the student. Identify/introduce the child to school support staff (e.g., counselor, social worker, and administrator) to whom the child should go to for emotional help
• Ensure the student’s confidentiality and right to privacy are maintained
• At quarter, trimester, and semester times, ensure that teachers and staff members new to contact with the student are trained/reminded
• Ensure that the office secretary/aide who meets substitute teachers when they arrive reminds the substitute teacher to be sure to look in the substitute folder for the names and information about students with medical needs
• Ensure that every teacher has a substitute folder that includes the names, information, and pictures (if possible) of students with medical needs
• Understand and implement federal and state laws regarding students with diabetes
• Genuinely welcome the parent and student to your school
• Support the parent/child in working with “reluctant” teachers or other school staff
• Work with the parent and other appropriate personnel to develop a 504 Plan
• Ensure that the student receives the needed modifications and accommodations

Recommended School Nurse Responsibilities

• Clarify roles and responsibilities with trained school personnel (roles for the other trained school personnel are listed in the rest of this section)
• Maintain or gain familiarity with current standards of care for children and teens with type 1 diabetes
• Work with an interdisciplinary team to implement the Health Care Plan and Section 504, IEP, or other education plan, and then monitor compliance
• Coordinate care at school and school-sponsored events for students with diabetes, and serve as a liaison between the school and the students’ families or make sure there is a trained school staff member who is responsible for this coordination
• Train or coordinate training of school personnel in diabetes care
• Perform or assist with students’ diabetes care in accordance with their Health Care Plan including blood glucose monitoring and insulin and glucagon administration
• Be available on site throughout the school day and when students with diabetes are involved in field trips, extracurricular activities, or school-sponsored events or make sure trained school personnel are available. Carry emergency diabetes supplies
• Serve as a resource for school personnel regarding up-to-date information about diabetes
• Advocate for the student with less–accommodating school staff
• Respect the student’s confidentiality and right to privacy
• Communicate regularly with the parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other diabetes supplies are low and need replenishing
Recommended Student Responsibilities

- Participate and contribute to the best of your ability in the discussions of how the school will help you manage your diabetes
- Clearly communicate to school personnel how you are feeling
- Understand what you are to do if an adult at school doesn’t give you permission for something you know you need to do (e.g., doesn’t let you test your blood or go to the nurse for food.)
- Learn what to say to students who make inappropriate or mean comments to you about your diabetes
- Know how you will handle the situation if food that isn’t good for you is passed out during class or other times
- Do not take advantage of the accommodations and modifications that the school is providing
- Make sure you have your supplies (blood testing meter, etc.) with you when needed
- Talk to the school counselor, social worker, or other appropriate school staff member about problems you may be having. These can be long-term emotional problems or even simple problems, such as you’d rather have your snack at 10:30 a.m. instead of 10:45 a.m.
- Work to become as independent as possible in your own diabetes care and management
- Do not let any other student use or have any of your diabetes supplies (e.g., syringes, glucose tablets)
- Don’t be afraid to let good friends know about your diabetes and how they might help if you ever need assistance

Recommended Teacher/Staff Member Responsibilities

- If the student with diabetes states he/she doesn’t feel well, NEVER send the student to the nurse’s office without another student or adult accompanying him/her!
- Genuinely welcome the student with diabetes into your classroom and create a supportive environment for him/her
- Assure the parent that you will do everything in your power to keep the child safe
- Willingly give time to be trained in understanding diabetes and the care of the student
- Advocate for the student with less accommodating school staff
- Create a “system” for a regular reminder to yourself to be vigilant and observant concerning the student with diabetes. Use the same system to remind yourself of low/high blood sugar symptoms and emergency responses
- Create a “system” to make sure that when field trips or other special/different kinds of activities are planned, that the child whose diabetes needs are remembered and addressed
- Provide agreed–upon modifications and accommodations to the student. Don’t make the student and parents jump through hoops if another modification/accommodation needs to be added to the agreed upon list. Find ways to help the student feel less “different”
- When you are out of the classroom, ensure that the substitute or other person covering your classroom knows what to look for, what to do, and what modifications or accommodations are necessary. Have a Substitute Teacher Folder in an obvious place and include the appropriate information on the student with diabetes. See Substitute Teacher Form in the Educate the Educator section
- Communicate regularly with the student’s parents. Use them as a resource and partner with them to provide the best learning environment possible. Let parents know when snacks or other needed supplies need to be replaced
- Respect the student’s confidentiality and right to privacy
- Work with the parent and child to determine how to address diabetes issues that may arise in the classroom
Other Staff Responsibilities

**PE Teacher & Coach**
- Read and carefully follow the written care plans, including the 504 or IEP, and the Health Care Plan
- Clearly understand the impact of exercise/high intensity physical activity on the blood sugar levels of a student with diabetes
- Always have available a cell phone or other communication device to contact the school office or 911 in case of an emergency (e.g., low blood sugar/insulin shock) when outside the school building, in athletic facilities, or at away games
- Always have quick-acting food/drink on hand (e.g., glucose tablets, orange juice)
- At away games, have glucagon available and train and practice its administration
- Train and practice in the use of the student’s blood-testing equipment
- Communicate regularly with the student/athlete with diabetes to discern his or her readiness/ability to participate in physical activity or game situations; listen to what the student with diabetes says and follow his or her lead
- Allow the student/athlete with diabetes to carry water and food with him/her at all times and eat/drink in class or at practice/games

**School Counselor**
- Learn about, support, and respond to – as appropriate – the emotional needs of students with diabetes
- Promote and encourage independence and self-care consistent with student’s abilities

**Food Service Staff**
- Provide students with diabetes and their families with lunch menus in advance that include the nutritional content of menu selections (including calories and grams of carbohydrates, sugar, protein and fat)
- Ensure that students with diabetes have easy and timely access to food and enough time to finish their meals
- Allow students with diabetes to eat first if low blood sugar (hypoglycemia) symptoms are present

**Bus Driver**
- Know which students on your bus route have diabetes
- Have emergency instructions regarding diabetes care on the bus
- Be aware of where students normally keep their supplies
- Permit students with diabetes to eat snacks on the bus, if necessary
The Most Important Rules

Rule # 1

The number one and most important rule is: When a student with diabetes says he/she doesn't feel well or thinks he/she is having a blood sugar problem, NEVER, EVER send the student to the nurse’s office without another student or adult accompanying him or her! This one is worth repeating. A student with diabetes who is beginning to have an insulin reaction (low blood sugar) may not be capable of getting to the office on his or her own. Remember that some of the symptoms of low blood sugar are erratic behavior, confusion, and inability to concentrate.

It is imperative that a student with diabetes has an adult or dependable student go with him or her to ensure that the student makes it to the office. Failure to follow through on this rule could result in a life-threatening emergency. It is also a good idea to use the intercom or classroom phone (or the teacher’s cell phone) to call the nurse’s office to let him or her know that the student is on the way.

(If possible a better practice would be to have the treatment/nurse come to the student versus the student going to the treatment/nurse.)

Rule # 2

The second rule is, when in doubt, if a student with diabetes is experiencing a blood sugar problem, and a blood testing meter is unavailable to determine whether the blood sugar level is high or low, treat for low blood sugar. In other words, when in doubt – have the student eat. Test as soon as possible to determine a further course of action.

Rule # 3

If a student with diabetes is beginning to shake, lose consciousness, or experience convulsions, lay the student on the floor on her side. This is to prevent further injury to the student and to prevent choking.
Educate the Educator: Staff Training

- Identification of staff for training
- Diabetes care team school–year plan
- Diabetes care team meeting talking points
- Sample letter for the diabetes care team
- Sample letter for classmates’ families
- Diabetes management overview for staff/substitute teachers
- Potential academic and school rule modifications
- Emotional issues involving the student
- Extracurricular/after-hours school events
- Tips for Coaches
- Notification/training of substitute teachers
- Field trip checklist
- Educational tools and templates
Educate the Educator

In caring for children with type 1 diabetes, educational professionals must understand the importance of their involvement in the child’s diabetes management. Young children, including school-aged children, need assistance with their diabetes care, while middle and high school students can often manage their own diabetes more independently. Each student is different, thus, education and training on how to care for a child and adolescent with diabetes must be an ongoing group effort of the parents, school staff, and the student with diabetes.

When a student has been newly diagnosed, it is critical that the parent initiate a partnership with the school to care for his diabetes. Many teachers may only have had past experience with older relatives with type 2 diabetes. For this reason, it is important to start with the basics in your training. Included in this section are training tools that might assist with educating your child’s teacher and training school staff in diabetes management.

Effective diabetes management at school has numerous positive outcomes. It can:

- Promote a healthy, productive learning environment for students with diabetes
- Reduce the number of absences of students with diabetes
- Reduce classroom disruptions and disturbances
- Help ensure an effective response in case of a diabetes-related emergency

Identification of Staff for Training

Following is a list of staff members who should be considered for diabetes training.

- Principal
- Assistant Principal
- Dean
- Nurse
- Health aide
- Guidance counselor
- Social worker
- Psychologist
- Academic teacher(s)
- Physical education teacher
- “Specials” teachers (music, art, etc.)
- Librarian
- Classroom aides
- Cafeteria manager and lunchroom monitors
- Hall monitors
- Bus drivers/bus driver manager
- Coaches
- Sponsors of clubs that the student might join
- Secretaries
- Band/orchestra teacher
Diabetes Care Team
School–Year Plan

(Your child’s name) Diabetes Care Team
Plan 200_ - 200_ School Year

Step 1: Contact school to request care team meeting, teacher assignment, and schedule for the next school year
When: April/May

Step 2: Provide introduction to diabetes/diabetes care, emergency kits and instructions to:
Who: Nurse and Administration. Nurse should provide copies of care plan
When: Shortly after contacting school to set up meeting. Familiarity with these materials before the meeting will lead to more active and productive team meetings.

Step 3: Diabetes Care Team Meeting – Preliminary Session
Who: Classroom Teachers, Administration, Nurse, and Parents
When: Preferably before the end of the school year
* Inquiry: What is your familiarity with diabetes?
* Overview of materials: What is diabetes? What is involved with daily care?
* Tools: Glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
* Overview of materials: Highs and lows, symptoms, emergencies, treatment, effects
* Glucagon demonstration and exercise
* Influences: Schedule (timing, activity), meals/snacks, other hormones, illness
* Question and answer period

Step 4: Diabetes Care Team Meeting – Group Session
Who: Classroom & Specials Teachers, Nurse, Administration, Counselor, Parents, Child
When: Prior to the start of the new school year
* Inquiry: What is your familiarity with diabetes?
* Overview of materials: What is diabetes? What is involved with daily care?
* Tools: Glucose meter, pump, mini backpack, emergency kits (glucagon), instructions
* Overview of materials: Highs and lows, symptoms, emergencies, treatment, effects
* Glucagon demonstration and exercise
* Influences: Schedule (timing, activity), meals/snacks, other hormones, illness
* Question and answer period

Step 5: Follow–Up
* E-mail links to additional resources/more detailed information (following meeting)
* E-mail nurse for progress/issues report (1 wk, 2 wks, 1 mo, 3 mo)
* E-mail reminder to send home perishables in emergency snack kits over the holidays
* Replenish perishables in emergency snack kits upon student’s return in January
* E-mail reminder for kits and supplies to be sent home the last day of school
* Check in frequently and offer thanks readily
Diabetes Care Team Meeting Talking Points

- Student has type 1 diabetes and requires insulin so his/her body can use the food he/she eats. Daily care requires a regimen of checking blood glucose levels throughout the day to monitor the effects of food intake, insulin, time, activity, other hormones and illness
- He/she uses a blood glucose (BG) monitor or “meter”. The meter sends the level to his/her insulin pump using RF communication. We’ve programmed the pump with settings so that it can calculate a dosage of insulin based on that BG level, “active” insulin, and the grams of carbohydrates to be eaten. His/her supplies are kept in his/her backpack and back-up supplies are located in emergency kits throughout the school. Emergency glucagon injection kits with instructions (orange) are in his/her backpack, nurse’s office, and PE pack
- “Normal” BG levels are 80-120. (Child’s name) “target” level at school is 100-200. Low BG levels occur when there is too much insulin and/or too much activity and not enough sugar in the body. Immediate action (giving sugar) is necessary to prevent nerve/brain damage, loss of consciousness and/or seizure. It can take 10 minutes for sugar to get into the bloodstream, so a short break or rest is also helpful. Signs to look for include pallor, nausea, frustration and uncharacteristic or emotional behavior. He/she typically feels shaky. Prolonged periods of high BG levels (above 240) occur when there is not enough insulin and can cause acid levels to build up in the body, which can cause vomiting, dehydration or coma
- Therefore, we must commit to a daily regimen designed to prevent avoidable emergencies and we must prepare for influences which can put (Child’s name) at risk such as changes to the schedule - timing, activity, meals and snacks - as well as illness, hormonal changes, and stress
- Glucagon demonstration and exercise

A Few Reminders…

- Checks can be done anywhere and at anytime. It’s best to wash hands or use an alcohol wipe prior to checking. His/her trash capsule is emptied at home
- If child feels low, it’s OK and preferable to drink a juice box before checking
- Treat lows immediately according to guidelines on daily sheet - do not call home first
- (Child’s name) should have backpack with his/her always. No one else should carry it or open it
- His/her food is “counted,” so she must finish all food that is packed. Call if there is a spill or problem
- If in doubt, ALWAYS call
- If his/her pump alarm goes off, it has a message…time to check BG, low insulin or low battery. He/she should respond with the appropriate action
- If he’s/she’s been ill or fighting off an infection or after a break, occasionally extra BG checks may be necessary. Otherwise, he/she will check before snack, lunch and administer a “bolus” of insulin. He/she will also check before getting on the school bus
- ALWAYS be on the lookout for things that threaten the regimen. Please e-mail me or call with changes to the schedule which affect the activity level and/or timing of snack or mealtime, so we can ensure my child’s safe participation in activities such as assemblies, standardized testing, celebrations, lessons with food, treats, birthdays, field trips, field day, delayed starts, early dismissals, substitutes, nurse/specials substitutes, fire drills, and lock-down drills

Thank you for your care and support!
Dear (School Name) Diabetes Care Team,

Our daughter (child's name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with diabetes but do not know much about the actual disease. It is our desire to share some information that will give you both comfort and confidence as you support (child's name) in caring for her diabetes at school.

(Child's name) is very comfortable talking about her diabetes. She doesn't like to consider herself to be “different” from other children and we strive to make the mechanics of her care so routine that it seems invisible to those not looking for it. She is accustomed to the requirements at each snack and mealtime: checking her blood sugar beforehand, eating and finishing “counted” foods and “pumping” insulin. Occasionally, she may need an extra snack or water. Otherwise, she can do all of the same things as anyone else.

During the school year, there are special occasions, learning experiences and celebrations, which include food and treats. With minimal planning and coordination, we can easily develop a plan for any event, activity or change in schedule – but advance notice isn't always possible. Since (child's name) inclusion hinges on our ability to coordinate her participation, please know that we are just a phone call away at any time for questions, concerns or feedback.

Many thanks for your care and support,

Parent’s name

Our contact information is:

Home: ___________________________

Dad’s Work: _______________________

Mom’s Work: _______________________

Dad Cell: _________________________

Mom Cell: _________________________

Physician: _________________________

Physician address: _________________________

Physician phone number: _____________

Continued
**What is Diabetes?**

Diabetes is a chronic disease that impairs the body’s ability to use food properly. Under normal circumstances, the hormone insulin, which is produced in the pancreas, moves sugar to the cells of the body to convert food into energy. In people with diabetes, either the pancreas doesn’t make insulin or the body cannot use insulin properly. Without insulin, glucose - the body's main energy source - builds up in the blood and causes severe damage.

Children with diabetes usually have insulin-dependent (type 1) diabetes, in which the pancreas doesn’t make insulin. They need daily insulin injections or wear an insulin pump to enable their bodies to use food properly. Two kinds of problems occur when the body doesn’t make insulin.

Hyperglycemia occurs when blood glucose levels get too high - for example, when the body gets too little insulin or too much food. Blood glucose also rises when a person with diabetes is ill or under extreme stress. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may develop into ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin.

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when blood glucose levels get too low - for example, when the body gets too much insulin, too little food, or too much activity or stress. Hypoglycemia is the most common problem in children with diabetes. Usually it is mild and can be easily treated by giving the child a sweet food or drink.

**Diabetes is not contagious. You cannot “catch” it from someone who has it.** Diabetes can run in families. Researchers are still studying how and why diabetes occurs in certain children and families. Children cannot outgrow type 1 diabetes. Although there isn’t a cure for diabetes, it can be controlled. Research has shown that maintaining good control of blood glucose levels can possibly prevent or at least postpone some of the long-term complications of diabetes.

Diabetes care is more flexible today than it used to be. With good medical care and support from other children and adults, children with diabetes can lead healthy, active, fulfilled lives.
Dear Fellow Parents of Mrs. Webster’s Third Grade Class,

Our daughter (child’s name) was diagnosed with insulin-dependent (type 1) diabetes just after her second birthday. Most people know someone with diabetes but do not know much about the disease. Since (child’s name) is in your child’s class, we wanted to provide some information for you to share with your child. Also, Mrs. Webster will read a book to the class, Taking Diabetes to School by Kim Gosselin, and have (child’s name) talk about what she does to take care of her diabetes.

(Child’s name) is very comfortable talking about her diabetes, wearing an insulin pump, and taking her backpack of supplies with her wherever she goes. She doesn’t consider herself to be “different” from other children and we refrain from referring to her as a “diabetic.” She is accustomed to a daily routine that helps to control her diabetes. At each snack and mealtime she must check her blood sugar, eat and finish “counted” foods, and calculate a dose of insulin to match her intake. To make the calculation, we must count up the total grams of carbohydrate that she will eat and her pump’s computer determines the right amount of insulin.

When there is a class celebration or if you send in treats for the class, we can plan for (child’s name) to take part if we know the “count” to use. She is not on a restricted or special diet. (Child’s name) can eat anything sweetened with sugar, Splenda or Nutrasweet, but she avoids other artificial sweeteners and sugar alcohol since they cause severe digestive discomfort. Thank you for your cooperation in planning for an amazing year for all of our children!

We hope you will call us if you have any questions. Thank you!

Sincerely,

Parent’s names
Phone number

What is Diabetes?

Diabetes is not contagious. You cannot “catch” it from someone who has it. Diabetes can run in families. Researchers are still studying how and why diabetes occurs in certain children and families.

Diabetes is a chronic disease that impairs the body’s ability to use food properly. The hormone insulin, which is produced in the pancreas, helps the body to convert food into energy. In people with diabetes, either the pancreas doesn’t make insulin or the body cannot use insulin properly. Without insulin, glucose - the body’s main energy source - builds up in the blood.
Children with diabetes usually have insulin-dependent (type 1) diabetes, in which the pancreas doesn't make insulin. They need daily insulin injections to enable their bodies to use food properly.

Two kinds of problems occur when the body doesn't make insulin. Hyperglycemia occurs when blood glucose levels get too high - for example, when the body gets too little insulin or too much food. Blood glucose also rises when a person with diabetes is ill or under extreme stress. The body produces ketones, harmful acids that poison the body and its organs. Untreated, hyperglycemia may develop into ketoacidosis, a very serious condition that requires hospitalization. Treatment includes extra fluids and insulin ([Child's name] drinks extra water and may have to skip a snack).

Hypoglycemia is the exact opposite of hyperglycemia. It occurs when blood glucose levels get too low - for example, when the body gets too much insulin, too little food, too much activity or stress. Hypoglycemia is the most common problem in children with diabetes. Usually it is mild and can be easily treated by giving the child a sweet food or drink ([Child's name] uses fruit snacks or a juice box).

Children cannot outgrow insulin-dependent diabetes. Although there is no cure for diabetes, it can be controlled. Research has shown that maintaining good control of blood glucose levels can prevent or postpone some of the long-term complications of diabetes.

Diabetes care is more flexible than it used to be. With good medical care and support from other children and adults, children with diabetes can lead healthy, active, fulfilled lives.
Diabetes Management Overview for Staff/Substitute teachers

Overview – Daily Care

Eight year-old (child’s name) is a child with insulin-dependent diabetes attending the third grade at (school name). She wears an insulin pump that continuously gives her insulin. Her mini backpack contains the necessary items to perform the frequent blood sugar checks that help to control her diabetes, avoid low blood sugar emergencies, and prevent long-term complications. Both must be with her at all times.

(Child’s name) is capable of checking her blood sugar level and programming her pump under supervision. At this age, she requires support evaluating numerical results to determine the action required. Every day, she must maintain a regimented schedule and prepare for any changes or adjustments to that schedule. Since her pump calculates insulin amounts based on the grams of carbohydrates eaten at each snack and meal, it is extremely important to make sure that she always finishes all of the food that is “counted.”

All adults who come in contact with the child (classroom and specials teachers; substitutes and school administration) should be made aware of the child’s medical condition, symptoms of low and high blood sugars and emergency care. On a daily basis, those familiar with (child’s name)’s, personality, demeanor and behavior should keep in mind recognizable symptoms of low blood sugar and act immediately when symptoms are exhibited, reminding him/her to consider how he/she feels, and having him/her perform a blood sugar check if in doubt. Ignoring symptoms or using a “wait and see” approach can quickly lead to an otherwise avoidable emergency situation such as discussed below.

(Child’s name)’s target blood sugar range is __________ during school hours. Sudden drops in blood sugar levels lead to “insulin reaction,” low blood sugar emergencies. Levels below 65 cause brain and/or nervous system damage; levels below 45 can cause seizure, coma or even death. Daily log sheets kept in his/her mini backpack display up-to-date blood sugar level guidelines/charts to consult whenever a check is performed; making it easy to prevent emergencies and administer treatment for “lows”. High blood sugars are less worrisome over a short period of time and should be treated with extra fluids and/or corrected with insulin when discovered, unless accompanied by nausea.

In the case of a seizure, convulsions, or loss of consciousness due to severely low blood sugar, a glucagon injection must immediately be administered by the school staff. 911 should be called before administering the glucagon, but there should be NO delay in administering the glucagon while waiting for the ambulance to arrive.

Potential Academic and School Rule Modifications

Academic and school rule accommodations and modifications should be tailored to the unique needs of each student with diabetes. Factors such as age and maturity, illness, and stress can impact when accommodations and modifications might be necessary. Accommodations and modifications may include:

- Allow food to be stored/eaten in the classroom
- Allow insulin injection in classroom or nurse’s office
- Allow the student to carry a minipack for diabetes supplies
- Allow food to be stored in student’s locker
- Allow student to have/eat food on field trips or other outside school activities
- Allow student to have a water bottle or quick access to water
- Allow student to test blood sugar level in the classroom and/or other school areas and/or to leave the classroom to go to the nurse’s office as often as needed
- Allow student access to bathroom as often as needed
- Allow student to be first in the lunch/cafeteria line
• Allow student to determine level of participation in strenuous physical activities without penalty
• Allow student to keep a cell phone on his/her person (Clearly define that the only appropriate use of the cell phone is for diabetic emergencies. At all other times, school rules for cell phone use should be followed!)
• Provide storage areas for food or equipment
• Provide additional time for academic tests (including standardized tests)
• Allow student to test blood sugar level/eat before tests (including standardized tests)
• Allow student extra time for homework completion
• Provide modified homework or tests
• Provide additional academic help (and assign no penalties) after illnesses/absences/missing instruction due to diabetes issues
• Assure that the nurse and other staff are appropriately trained in diabetes care and management and emergency treatment
• Assure student’s full participation in all school activities with necessary assistance
• Provide counselor or social worker services
• Delay testing if blood glucose levels are too high or too low

The parent(s), student, principal, and/or guidance counselor should discuss the modifications/accommodations with the student and the need for the student to not take advantage of any changes in classroom and school rules.

Emotional Issues
Involving the Student

When a student is diagnosed with type 1 diabetes his/her whole life changes in an instant. All of a sudden he/she can’t eat and drink the things all of his/her friends are eating and drinking. After the baseball game, everyone runs to the ice chest to get a soda, but he/she has to find diet soda. He/she may be looking forward to a class or activity all day, but then his/her blood sugar acts up and he/she has to miss it. As if these challenges are not enough, he/she also has to deal with prejudice and teasing from other students, and sometimes even adults, who don’t understand the disease.

Although some students are very open about their diabetes, most don’t like to be considered “different.” Once again, the age when diabetes onset occurs, and the age, maturity level, personality, and emotional state of the student all affect how he/she will adjust to life with diabetes. Diabetes is stressful at any age, but particularly during adolescence when a student is most craving his/her independence. Conflicts between the student and his/her parents and teachers are almost inevitable, but having an understanding support network to help him/her work through these issues can do wonders for his/her emotional well-being.

Creating a support network requires discussions between the parent(s), student, nurse, administrator, guidance counselor, and teachers; these should always include consideration of emotional and social issues. The student’s desire for privacy should be respected whenever possible. Some emotional/social issues to consider include the following:

• Where will testing of blood sugar levels take place?
• Where will snacks be eaten?
• Will the student simply state to the teacher that he/she needs to see the nurse or does a “signal” need to be established between student and teacher for the student to communicate this need? (Either way, don’t forget to send another student or adult with the student with diabetes!)
• Will classmates be told/educated about diabetes and the student with diabetes?
• Who will do the talking/educating, and how?
• How will parties/food be handled so that the student is not left out or put in an embarrassing situation?
• Will the student wear an insulin pump during physical education class (if not, where will it be stored?)
• Will the student wear a medical ID bracelet?
• How will the school and/or the parent deal with the student if he/she resists care, does not take his/her insulin, refuses to check blood sugar levels, reports false glucose levels, etc.?
• If the student with diabetes manipulates his/her insulin/food intake to gain or lose weight, how will that be handled?
• How will depression or anger issues be handled?
Extracurricular/After-Hours School Events

Students with diabetes, like other students, should be encouraged to participate in extra-curricular activities. Being in the play, working on the yearbook, playing a sport, participating in intramurals, joining a club, joining the band, attending the school dance/activity night – all of these activities contribute to the future success of any student and can support the student with diabetes both physically and emotionally.

It is important to have a staff member who is informed, trained, and capable of caring for the student with diabetes in the case of low or high blood sugar issues at any of these extra-curricular or after-hours school activities. For most of these activities, the sponsor or leader of the activity would be the ideal choice to support the student's diabetes management. In the case of a school dance/activity night or similar kind of event, it would certainly be reasonable to expect that parents might want to volunteer to attend.

Tips for Coaches

How to help a young athlete with diabetes

- Review the athlete's diabetes management plan
- Know how to check blood sugar levels
- Know how to recognize and learn to treat hypoglycemia (low blood sugar), including how to administer glucagon
- When the student experiences and treats low blood sugar, it is still critical to have him/her sit out for a period of time in order to recover and allow the body time to bring the blood sugar up within the target range
- Know how to recognize and learn to treat hyperglycemia (high blood sugar), including how to administer insulin
- Allow the athlete to eat whenever and wherever necessary
- Allow extra trips to the bathroom or water fountain if needed
- Allow the athlete to miss occasional practices for medical appointments
- Pump sites can be a sensitive topic with regard to athletics; be aware that the student must determine if/where to wear their pump during practice/competition

Notification/Training of Substitute Teachers

In the ideal school world, all substitute teachers at a school would receive the same diabetes training that regular teachers receive. Unfortunately, there is sometimes a good deal of turnover in available substitute teachers during a school year. "Regular" substitutes move and/or get full-time teaching positions. New people move into the area during the school year and apply to be a substitute teacher. It is difficult to keep up with these changes and ensure that all substitute teachers in a building are fully aware and trained to deal with students with diabetes.

Due to these challenges, the school should do the following:

- Ensure that the secretary who meets substitutes as they arrive has set up a system for alerting subs when a student with diabetes will be in one or more of their classes. These substitute teachers should be told specifically to look for the diabetes information sheet in each teacher's substitute folder. The secretary should emphasize to the sub Rule #1: If the student with diabetes states he/she doesn't feel well, NEVER, EVER send the student to the nurse's office without another student or adult accompanying the student!
- Ensure that every teacher with a student with diabetes in his/her classroom has a substitute teacher folder with emergency information about the student with diabetes.
Field Trip Checklist

- Contact parent to discuss duration and location of field trip to determine the student's needs, the location and contact numbers of parents during the field trip, and to get an updated contact list with emergency phone numbers

- Ensure that at least one chaperone is trained in the student’s diabetes regimen

- Ensure that the student has the right amount and types of food (lunch and snack) plus extra food and plenty of water

- Ensure that the student has fast--acting (high sugar) liquids (e.g., orange juice, cola), glucose tablets, and glucagon in case of low blood sugar

- Ensure that the student has a blood glucose meter, testing strips, lancets, antiseptic wipes (staff should bring gloves if student will not test independently) and logbook

- Ensure that the student has enough insulin, the right types and syringes

- If the student wears an insulin pump, be sure he/she has the pump and related supplies

Other, as specified by parent or student's physician

Notes:
Substitute Teacher: Emergency Medical Form

The following student has type 1 diabetes. Please read this information carefully as failure to react properly can result in a potentially life-threatening situation.

Name of student ____________________________

Student is in my class during the following time period(s):
____________________________________________

Student should never be sent to the nurse or out of class without another adult or trusted student with him/her!

Symptoms indicating a problem may be occurring
(Common symptoms for this child have been circled)

- Dizziness
- Blurry vision
- Crying
- Irrational behavior
- Hunger
- Lightheadedness
- Erratic response to questions
- Frequent urination
- Exhaustion
- Convulsions
- Nervousness
- Shakiness
- Sluggishness
- Sweating
- Confusion
- Irritability
- Unable to concentrate
- Stomach pain
- Fruity odor on breath
- Personality change
- Nausea
- Pale coloring
- Poor Coordination
- Headache
- Drowsiness
- Thirst
- Lethargy
- Vomiting
- Unconsciousness

If one or more of the above symptoms are occurring, call for immediate assistance. Use the school intercom system, in-class telephone, or a cell phone – or immediately send another adult or trusted student to get help. If needed, obtain help from a nearby teacher. If the student with diabetes is unconscious or having convulsions, you should immediately:

1. Place the student on the floor, preferably on his/her side
2. Call for immediate school assistance.
3. Call 911

The following are special accommodations for this child (e.g. ok to eat in class, go to restroom).
High Blood Sugar Help Sheet

**Symptoms:**
- Thirst (dehydration)
- Frequent urination
- Blurry vision
- Stomach pain
- Increased hunger
- Nausea
- Lethargy, drowsiness, exhaustion
- Confusion
- Sweating
- Fruity, sweet, or wine-like odor on breath
- Vomiting
- Inability to concentrate

Response:

1. **If blood test results are slightly high** ________ (insert blood sugar level)
   - Regular activity may continue
   - Drink water or sugar free drinks
   - Monitor by testing regularly to see if blood sugar continues upward
   - Chart test results

2. **If blood test results are moderately high** ________ (insert blood sugar level)
   - No strenuous exercise
   - Drink water
   - Possible additional insulin (by chart or by instructions from physician or parent)
   - Monitor by testing regularly to see if blood sugar continues upward or comes down
   - Chart test results

3. **If blood test results are very high** ________ (insert blood sugar level)
   - No strenuous exercise
   - Drink water
   - Additional insulin (by chart or by instructions from physician or parent)
   - Ketone test if advised by physician or parent
   - **If student has ketones, contact parent immediately**
   - Monitor by testing regularly to see if blood sugar continues upward or comes down
   - Chart test results

*Please have your child’s doctor enter blood glucose ranges*
**Low Blood Sugar Help Sheet**

### Mild to Moderate Symptoms:
- Dizziness
- Nervousness
- Personality change
- Blurry vision
- Shakiness
- Nausea
- Crying
- Sluggishness
- Pale coloring
- Irrational behavior
- Sweating
- Poor coordination
- Hunger
- Confusion
- Headache
- Lightheadedness
- Irritability
- Drowsiness
- Erratic response to questions
- Unable to concentrate

### Severe Symptoms:
- Convulsions
- Unconsciousness

### Response:

1. **If blood test results are slightly low and student is alert and lucid**
   - No exercise
   - If it’s almost lunchtime – eat lunch (student should be accompanied to make sure he/she gets to lunchroom and is eating); after eating, student should test again to make sure blood sugars levels are back within target range; may need an additional snack somewhat later in day
   - Any other time – eat a snack; after eating, student should test again to make sure blood sugars levels are back within target range; may need an additional snack somewhat later in the day
   - Continue to monitor by testing regularly to see if blood sugar comes up

2. **If blood test results are low and student is showing signs of low blood sugar but is able to eat**
   - Immediate food intake (quick-acting source of glucose e.g. juice, glucose gel or tablets)
   - Additional food intake may be necessary (e.g. crackers)
   - Direct monitoring of student by nurse or trained personnel until blood sugar levels return back within target range

3. **If blood test results are low and student is showing signs of low blood sugar and is UNABLE to eat (student may be unconscious and/or experiencing convulsions and/or unable to swallow)**
   - Position student on floor on side to prevent falling/injury or choking
   - Call nurse or other knowledgeable staff member
   - Call 911
   - Administer emergency glucagon shot
   - Call parent/ask office to call parent
   - Direct monitoring of student by nurse or trained personnel until blood sugar levels return back within target range
   - Additional food when student is able (e.g. crackers) if needed to keep blood sugar levels in target range
Emergency Contact Information

Student's Full Name _____________________________________________________________

Mother  Adam Smith  Mother's Name_____________________________________________________
Home Phone _____________ Work Phone _____________ Cell Phone ________________

Father  Adam Smith  Father's Name_____________________________________________________
Home Phone _____________ Work Phone _____________ Cell Phone ________________

1st Emergency Contact  Adam Smith  Mother's Name_____________________________________
Home Phone _____________ Work Phone _____________ Cell Phone ________________

2nd Emergency Contact  Adam Smith  Mother's Name_____________________________________
Home Phone _____________ Work Phone _____________ Cell Phone ________________

Physician/Endocrinologist ____________________________________________________________
Office Phone_______________ Other Contact Phone _______________________________________

Hospital of Choice ________________________________________________________________
Address ____________________________________________________________
Phone _________________________________________________________________________

Insulin information/dosages __________________________________________________________________________
____________________________________________________________________________________
Other medical issues or other medication taken __________________________________________________________________
____________________________________________________________________________________
The Rights of Your Child with Diabetes

- Your child’s rights
- Section 504
- Legal rights of the child with diabetes

- Common 504 Plan questions
- References for those who desire more information
Your Child’s Rights

An important part of building a good working relationship with your child's school is a discussion regarding the rights of your child. It is important that you are aware of these rights and the laws that protect your child relevant to her education. While most of you will never have a problem with your school, it is still a good idea to have a plan in place that protects your child and her educational services.

There are at least three federal laws that address a school’s responsibility to provide care to students with diabetes:

1. Section 504 of the Rehabilitation Act of 1973 (also known simply as Section 504)
2. The Americans with Disabilities Act of 1990 (ADA)
3. The Individuals with Disabilities Education Act (IDEA)

This section will give a general overview of these laws and how they protect your child. Additionally this section will provide you with the knowledge of how to effectively advocate for your child and initiate the programs and plans that protect her while in the school setting.

DISCLAIMER

The JDRF staff/volunteers compiling this manual are not attorneys and do not purport to give legal advice. While the information provided in this manual is believed to be accurate and up to date, JDRF makes no representations as to the accuracy or completeness of the information contained in this manual.

For more information about your child’s rights and the federal laws that govern services for children with diabetes, please see Appendix I.

Section 504

According to this law, parents of qualifying children have the right to develop a Section 504 Plan with their child's school. Any school that receives federal funding must comply with Section 504 laws, or they may lose the federal funds. This act further prohibits programs and activities that receive federal financial assistance from discriminating against anyone with a disability. You do not need to wait until discrimination occurs to seek the protections of this law. Rather, initiating a 504 Plan is a very proactive step in advocating for your child’s rights.

This law requires schools to identify educational needs and – when necessary – develop a “504” Plan. A 504 Plan is a legal (written) document specifying what “reasonable” modifications and accommodations the school must provide for a student with a disability (generally put into place for a student with a medical disability such as diabetes). A child does not need to require special education to be protected; children with type 1 diabetes are protected under this law.

Note on Standardized Testing

Under this law, high school students (and students in lower grades taking state tests) with diabetes can receive special accommodations when taking standardized tests (e.g., PSAT, AP, NMSQT, SAT, and ACT). These accommodations usually include “stop the clock” breaks for blood glucose testing, insulin administration, bathroom visits, or taking emergency glucose to treat low blood sugars. The organizations that administer the tests generally require that students have a 504 Plan on file before providing the accommodations. Students with type 1 diabetes should request the following accommodations: “extra breaks,” “extended breaks,” and “breaks as needed” on the SAT, and “stop the clock breaks within sections” on the ACT. These accommodations are in addition to any additional testing time that may be granted for learning disabilities, ADHD, or other special needs.

Accommodations often take months to be approved, so it is a good idea to file for them early. It is especially important to have college entrance exam approvals in place well before the planned testing date. Since college entrance exams are in all likelihood the most important exam that students take throughout their high school careers, it is imperative that students with type 1 diabetes receive the testing accommodations they need in order to do well on them. After all, the student's SAT and/or ACT scores will influence which colleges he or she is accepted into, and these outcomes can affect the path that his or her life will follow.
See Appendix II for more detailed information on precisely why and how to file the application for SAT and ACT accommodations.

**Americans with Disabilities Act (ADA)**

This law specifically prohibits all schools and day care centers except those run by religious institutions from discrimination against people with disabilities, including diabetes. Its definition of disability is the same as in Section 504 (includes diabetes).

The laws within this act say that your child with diabetes has the right to go to school, play a sport, join a club, and do everything else that kids without diabetes do. It further states that public schools and other covered organizations must make "reasonable accommodations" for your child's diabetes.

**Individuals with Disabilities Education Act (IDEA)**

Many students with diabetes do not qualify for IDEA protection, but it is important to know what it is in case you may qualify. This law covers children whose disability impairs their academic performance. It requires that such children be given a "free, appropriate public education." Qualification depends on how diabetes affects the student's ability to learn. If a student qualifies, he has the right to develop an Individualized Education Program (IEP) with his school. An IEP is similar to a Section 504 but includes specific measures to address your child's academic performance and needed special education and other related services.

**Additional State Laws**

Even though federal laws already provide protection for children with disabilities, some states provide greater protection to students with diabetes due to the passage of school diabetes care legislation. States with such legislation include:

- California
- Connecticut
- Hawaii
- Kentucky
- Massachusetts
- Montana
- Nevada
- North Carolina
- Oregon
- Oklahoma
- Rhode Island
- South Carolina
- Tennessee
- Texas
- Utah
- Virginia
- Washington
- West Virginia
- Wisconsin

Each state varies in its coverage. The most comprehensive laws are currently found in North Carolina, Virginia, and Washington.

**The Parent/School Partnership Continues**

504 Plans are a way for you to hold the school accountable for meeting your child's needs while in the school's care. Remember, though, that this is a partnership you are building with your child's school and all parties have a role in the 504 process.

**School's Role in the 504 Process**

It is the responsibility of the school and its personnel to have an understanding of diabetes and be trained in its management and in the treatment of diabetes emergencies. Knowledgeable, trained school personnel are essential to a student's safety and physical well being when dealing with immediate health risks of high or low blood glucose levels.

Furthermore, an individualized Diabetes Medical Management Plan (the 504 Plan) should be developed and signed by the school, the parent or guardian, and the child's diabetes management care team. The Diabetes Medical Management Plan (the 504 Plan) should address the specific needs of the child and provide specific instructions related to the following:

- Times/places for blood sugar monitoring, including accommodations for testing and treating
- Ensuring that staff members are trained in checking blood sugar levels, recognizing and treating high and low blood sugar symptoms, and administering both insulin and glucagon
• Allowing the student to eat whenever and wherever necessary, including eating lunch at an appropriate time and allowing enough time to finish eating
• Allowing extra trips to the bathroom or water fountain
• Ensuring the student’s full participation in all sports, extracurricular activities, and field trips, with the necessary care and/or supervision
• Permitting extra absences for medical appointments and sick days when necessary, without penalty

**Parent’s Role in the 504 Process**

In addition to submitting a formal request for a 504 Plan and a cover letter to the school, a parent or guardian is responsible for providing the school with the following:

• All materials and equipment necessary for diabetes care tasks, including blood sugar testing supplies and insulin administration (if needed). The parent is responsible for the maintenance of the equipment and must provide instructions to ensure the proper disposal of materials. A separate logbook should be kept at school for the staff or student to record blood glucose test results.

• Supplies to treat hypoglycemia, including a source of glucose and a glucagon emergency kit.

• Information about diabetes.

• Emergency phone numbers for the parent and the student’s diabetes doctor (and staff) so that the school can contact these individuals with diabetes–related questions or during emergencies.

• Information about the student’s meal and snack schedule. The parent should work with the school to coordinate this schedule with that of the rest of the class as much as possible. For young children, instructions should be given for when food is provided during school parties and other activities.

**Legal Rights of the Child with Diabetes**

If a school attempts to discriminate against your child with diabetes or is unable or unwilling to commit to some agreement with the parents and child about how the child will be provided equal opportunity to participate in academic, extracurricular, or other school activities, then schools can be compelled by the legal system to provide these services.

It is suggested that the following steps be followed in such cases:

1. If the parents, school, and student cannot come to a mutual agreement about a 504 Plan or the parents suspect that the school isn’t abiding by the agreement, the parents must request in writing that a 504 meeting take place. Prior to the meeting, the parent should review sample 504 Plans (see Educate the Educator section) and prepare a list of modifications and accommodations they feel are appropriate. The parent has the right to bring a friend, advocate, or lawyer to the 504 meeting to assist in the discussion.

2. On rare occasions, the student’s academic performance may be so adversely affected by diabetes complications that he/she may need special education services. In such cases it is the parent’s responsibility to formally request special education testing. Before this testing can take place, parents must give written permission to the school to administer these tests. The student must complete the testing and meet certain criteria to be eligible for special education services. If he/she is deemed eligible, an IEP (individualized education plan) is written and certified special education teachers become involved in the education of the child.

If your child is denied a 504 Plan or you feel he/she has been discriminated against, please contact your local chapter for resources related to being denied a 504 Plan and suggested next steps.

See Appendix I for more information on the legal rights of children with diabetes.
**Common 504 Plan Questions**

**Is a child with type 1 diabetes automatically eligible for a 504 Plan?**

The law does not provide any automatic eligibility for a 504 Plan. 504 eligibility is made on an individual basis. A team of people knowledgeable about the student must convene and determine eligibility. That being said, it would be highly unlikely that a student with type 1 diabetes would not qualify for a 504 Plan. Several life functions are certainly impacted which would provide the basis for eligibility (e.g. “caring for oneself” and “learning” come quickly to mind.) If a school has not suggested a 504 Plan, the parent should request, in writing, a 504 evaluation to take place. There are numerous sources (some included in this Manual) which can help a parent with writing this request as well as provide information on what is to be considered by the team to determine eligibility.

**Must the parent of a child with type 1 diabetes be a part of the 504 Team?**

The law provides for the parent to be notified of the result of the 504 meeting/evaluation/discussion but does not specifically say a parent must be present at the meeting. However, the law does state that the 504 team is made up of persons knowledgeable about the student, which implies that if a parent is not allowed to attend, there may be cause for complaint and a hearing. It would be hard to argue that the parent is not a knowledgeable person about the child.

**Must the 504 Plan be in writing?**

The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that they are providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and violation of Section 504. As one of the representatives from the Department of Education Office of Civil Rights stated, “OCR would have no concept how a district/school would prove a 504 Plan exists and the accommodations being made without the Plan being in writing.”

**Is there a requirement for an ANNUAL review of a 504 Plan?**

The law does not require an annual review. It does require a “periodic” review. If the 504 Plan is well written and includes a requirement for any new teacher or staff member who will be in contact with the child to be informed and trained, and nothing has changed in terms of the needs of the child, an annual review wouldn’t be necessary. This is one of those areas where parents can be sympathetic to school personnel time constraints. If the school is doing everything necessary and willingly trains the child’s teachers every year, and the 504 Plan already covers everything it needs to, then why make the school have an unnecessary meeting.

The law does require a “periodic” review. IDEA requires a review every three years and that should also probably be the maximum time frame a 504 Plan should go without a formal review. There would also have to be a formal review at any time a change is needed in the 504 Plan to meet the needs of the child. It also may be necessary to have a review when the child goes to a new school in the same district (e.g. elementary to middle school building or middle school to high school building.)

**Must the school provide a nurse or other trained person to provide services for my child (e.g. give insulin, test blood sugar, give glucagon in an emergency)?**

Yes. This should be written into the 504 Plan. Nurses get sick and are absent from school for that and other reasons, so it is very important to include in the 504 Plan that staff members in addition to the nurse be trained to provide these services.

Some states have laws that state that only licensed staff members can give medication and/or injections. California is one of those states. However, a recent California decision based on a lawsuit states that:

When federal and state laws are reconciled, it is clear that it is unlawful for an LEA [local school district] to have a general practice or policy that asserts that it need not comply with the IDEA or Section 504 rights of a student to have insulin administered at school simply because a licensed professional is unavailable. In such situations, federal rights take precedence over strict adherence to state law so that the educational and health needs of the student protected by the Section 504 Plan or IEP are met.
Can the school say they will not qualify a child with type 1 diabetes because the child is doing well academically and is socially responsible and personally independent?

Again, eligibility is not automatic for anyone and a team with knowledge about the child must evaluate and determine eligibility. However, Section 504 protects all persons with a disability who:

1. Have a physical or mental impairment which substantially limits one or more major life activities;
2. Have a record of such an impairment; or
3. Are regarded as having such an impairment.

In number one, above, major life activities are defined as functions such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning or working. A strong argument could be made that students with type 1 diabetes are substantially limited, especially when blood sugars are not normal, in caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, and learning. How can a school argue that when a student is in insulin shock, that this student's abilities in these areas are not substantially limited. A student in insulin shock cannot walk, speak, learn, or care for themselves. Learning would be substantially limited if a student with type 1 diabetes missed field trips, missed instruction due to high blood sugar, missed class due to being in the nurse's office testing blood, etc. A child with type 1 diabetes would also be eligible for a 504 Plan in numbers 2 and 3 above. Certainly a child with type 1 diabetes has a record of an impairment AND would be regarded as having an impairment.

There are certainly other arguments which can be made that a student with type 1 diabetes, who is doing well, is still eligible for a 504 Plan. Things do change and learning may be substantially impacted by changes in blood sugar due to a growth spurt, early adolescence (hormones), etc. School or teacher rules may prevent snacks in the classroom, which would need a 504 Plan to provide for an exception to this rule. School rules may prevent blood testing to occur in the classroom and again, a 504 Plan would be needed to provide for an exception to this rule.

A school that will not provide a 504 Plan because a student with type 1 diabetes is "doing well" is setting itself up for great trouble. This is a lawsuit against the school district waiting to happen if a school has not set up a 504 Plan with training for teachers, procedures for handling a child with type 1 diabetes ongoing needs as well as procedures for emergencies, and a written plan demonstrating that the school is providing full access to school activities and learning opportunities.

Can the school prevent my child with type 1 diabetes from wearing a diabetes ID bracelet?

Unless a school has a “no jewelry of any kind” rule (which VERY few schools have), a student should be able to wear an ID bracelet. If it’s written into the 504 Plan, the child should be able to wear it, no matter what the school rule. On occasion, there may be a legitimate safety reasons for a particular teacher or coach to ask the child to temporarily remove the ID bracelet (e.g. a shop class where power tools are being used and where a bracelet may be dangerous; a sport with a lot of physical contact where another child may be injured by the ID bracelet.)

What is the difference between IDEA and Section 504? What should I be requesting for my child with type 1 diabetes?

IDEA is an education act (and sometimes known as Special Education) and Section 504 is a Civil Rights Act. In practical terms, the vast majority of students with type 1 diabetes will fall under the Section 504 umbrella which is to prohibit discrimination on the basis of a disability. Most students with type 1 diabetes will have no reason to be involved in the world of IDEA. There are only two reasons a diabetic student might be eligible for IDEA.

- The impact on diabetes is so great that the student's learning is severely impacted (which might qualify the diabetic child for special education services under the other health impaired category, or
- The diabetic child has an additional disability (most likely not related in any way with diabetes) which demands an individualized education plan (IEP) e.g. mental retardation, autism, emotional disturbance, learning disability, etc.
What should I do to make sure that my child with type 1 diabetes has accommodations available for ACT/SAT tests and state standardized tests?

Accommodations for state standardized tests should be listed in a student’s 504 Plan. For the ACT test, there is a form to complete which is available at http://www.act.org/aap/disab/opt1.html. Note that one of the requirements is to “Enclose written documentation from your school describing in detail the accommodations you normally receive in school.” Some high schools may require a 504 Plan stating these accommodations before they would provide them to ACT. Note that another requirement is to provide “The name and phone number of a school official familiar with your current testing accommodations.” It would be a good idea to meet with the child’s counselor a few months before the test will be given to make sure that the counselor (or another identified school staff member) is able to respond if contacted by ACT.

The SAT has similar requirements such as:
- have documentation on file at your school that supports the need for requested accommodations and meets the Guidelines for Documentation, and
- receive and use the requested accommodations, due to the disability, for school-based tests.

For further information on the SAT test, go to http://www.collegeboard.com/ssl/student/index.html

Where do I go when I believe that the school is discriminating against my child with type 1 diabetes and not providing the appropriate services?

Step 1: Try one more time at the school level. Try to have a one-on-one, heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable.

Step 2: In almost all school systems, there is a special education coordinator or someone who is charged with being in charge of Section 504 issues. Again, be nice, be respectful, be understanding of school limitations, and have your list of items that are on your non-negotiable list.

Step 3: Contact the school superintendent with the same attitude and issues as above.

Step 4: Obtain the services of an attorney and file for a due process hearing.

Step 5: Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your non-negotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

Step 6: Contact the regional office of the Department of Education Office of Civil Rights for your state. Contact information is available at http://www.ed.gov/about/offices/list/ocr/addresses.html. Based on the advice of this agency, filing a formal complaint may be the next step.
Do private schools have to provide the same services as public schools?

1. If the private school does not receive federal funding, then the 504 Act does NOT apply. Therefore, the school would not have to consider or provide a 504 Plan. If the private school DOES receive federal funding, then they would have to provide the same services as public schools.

2. The ADA (American with Disabilities Act) applies to all schools EXCEPT those run by religious institutions. If this private school is run by a religious institution, then the parent is pretty much at the whim of what the school is willing to do and the parent/child have little recourse. If the private school is NOT run by a religious institution, then ADA applies and the school would be prohibited from discrimination against people with disabilities, including diabetes. “Reasonable accommodations” must be provided.

References for Those Who Desire More Information

A great deal of information about schools and students with diabetes is available, including sample 504 Plans, checklists for school personnel, details on the law and schools, information for teachers and other school personnel, help for parents, help for the child with diabetes, etc. The following list is just a sampling of such resources:

- Helping the Student with Diabetes Succeed: A Guide for School Personnel: This guide was produced by the National Diabetes Education Program and is a joint program of the National Institutes of Health and the Centers for Disease Control and Prevention and more than 200 other partner organizations. It is available at http://www.ndep.nih.gov/resources/school.htm

- Juvenile Diabetes Research Foundation: www.jdrf.org (Check the Diabetes in School link.)

- Children With Diabetes: www.childrenwithdiabetes.com

- American Diabetes Association: www.diabetes.org
Diabetes in the Day Care Setting and in the College Years

- Diabetes in the day care setting
- Diabetes in the college years
- For the student: going away from home
- Letter to the roommate
Diabetes in the Day Care Setting

First and foremost, remember that the laws just discussed in the previous sections apply to the parent with a child in day care as much as they do for a school-aged child. Day care centers (with the exception of religious affiliations) cannot legally deny your child access to their services because of diabetes. Many day care centers receive federal funding through Head Start or other child development government programs. Under these laws, diabetes is considered a disability, and it is illegal for day care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with disabilities.

Remember, all of the information in the previous sections of this guide also applies to the parent with a child in day care.

The parent/guardian and the child’s diabetes doctor should develop an individualized plan for the child’s day care; the plan should address the specific needs of the child and provide specific instructions for each of the following:

1. Blood glucose monitoring, including the frequency and circumstances requiring blood glucose checks.
2. Insulin administration (if necessary), including doses/injection times prescribed for specific blood glucose values, and the storage of insulin.
3. Meals and snacks, including food content, amounts, and timing.
4. Symptoms and treatment of hypoglycemia (low blood glucose), including the administration of glucagon if recommended by the student’s health care provider.
5. Symptoms and treatment of hyperglycemia (high blood glucose).
6. Checking for ketones and appropriate actions to take for abnormal ketone levels, if requested by the student’s health care provider.

Do day care centers have to take my child with type 1 diabetes?

Based on the American with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, it is illegal for schools and/or day care centers to discriminate against children with disabilities. In addition, any school that receives federal funding or any facility considered open to the public must reasonably accommodate the special needs of children with disabilities. The exception is child care centers that are actually run by religious entities. So, almost all day care centers are covered.

• Children with disabilities must have an equal opportunity to participate in the child care center’s programs and services. This means that if a day care center is full, a child with type 1 diabetes must be put on the list for openings. It does not mean that the child with type 1 diabetes must be taken ahead of other applicants.

• Centers have to make reasonable modifications to their policies and practices to integrate children, parents, and guardians with disabilities into their programs unless doing so would constitute a fundamental alteration of the nature of the child care program. Children with diabetes can usually be integrated into a child care program without fundamentally altering it, so they should not be excluded from the program on the basis of their diabetes.

• Centers must provide appropriate training to one or more employees and provide for the administration of insulin, glucagon, and blood testing and provide access to snacks and other appropriate food.

• The child’s parents are responsible for providing insulin, glucagon, blood testing equipment, training, and food necessary for the child’s care.

A special note: The Department of Justice has settlement agreements with KinderCare, La Petite Academy, and others which address the issue of admitting children with type 1 diabetes to their child care centers.
Diabetes in the College Years

It is important for parents to be aware that things change a bit at the college level. At the elementary and secondary levels, the school district is responsible for identifying, evaluating, and providing the appropriate services for students with diabetes. Colleges and universities, on the other hand, have no responsibility to identify diabetes or any other disabilities. It is the student’s responsibility to make his or her disability known and to request special accommodations. Once the student or parents have done that, the college should be willing to fulfill the requirements of Section 504.

One of the benefits of a student’s declaring his or her type 1 diabetes to the university disability office is that it will help protect the student from receiving a poor grade due to excessive absences or missed work due to diabetes-related illnesses. Most professors will be more apt to allow the student extra time to complete assignments or to help with missed work due to absences that result from diabetes.

As parents, you may want to inquire about special accommodations while exploring colleges with your teen in order to help guide his decision based on his specific needs. Once your teen is accepted to the college and you begin the enrollment process, housing applications, etc., you can work with a disabilities coordinator to complete the necessary paperwork. If your teen is living on campus, it is suggested that you put in writing any desired accommodations and the need for nutritional data from food services.

Regarding confidentiality: Most colleges will request that parents indicate on a special signed form who needs to know about the student’s disability. In most cases, the Dean of Students, the accommodations coordinator, food services, the RA, and professors need to know. That form does not give them consent to discuss your student’s health issues with other parents, students, or outside personnel who have no need to know why certain accommodations are being made.

Alcohol and Diabetes

It is no secret that many students consume alcohol during their college years. It is very difficult to control blood sugar in the presence of alcohol, and the presence of alcohol can impair the judgment needed to detect and treat hypoglycemia. Because of the possibility that some students will choose to drink while at school, we have included some important information about the effects of alcohol on the body.

Moderate alcohol usually causes the blood sugar to rise. If you choose to drink alcohol, it is best to do so only occasionally and when your diabetes and blood sugar levels are well-controlled. One drink of alcohol should be counted as two fat exchanges, and regular beer also counts as an extra 1 starch exchange.

While a moderate amount of alcohol can cause blood sugar to rise, excess alcohol can actually decrease your blood sugar level by preventing the liver from adding glucose to the bloodstream sometimes causing it to drop dangerous levels. Alcohol can also interfere with insulin efficiency, increase triglyceride levels, increase blood pressure, and cause flushing, nausea, increased heart rate, confusion, and slurred speech.

Following are a few ways for people with type 1 diabetes to drink more responsibly if they choose to drink:

• Do not drink more than two alcoholic drinks in a 24-hour period. (One alcoholic drink = 5 oz. glass of wine, 1½ oz. “shot” of liquor, or 12 oz. beer)

• Drink alcohol only with food

• Drink slowly

• Avoid “sugary” mixed drinks, sweet wines, or cordials

• Mix liquor with water or alternate between glasses of water and alcoholic beverages

Warning: Glucagon shots may be less effective in treating severe low blood sugars caused by drinking because of the effect of alcohol on the liver.
For the Student: Going Away From Home

Going away to college can be scary, especially if it’s your first real foray into working with type 1 diabetes professionals on your own. Your medical care team is critical to your physical well-being as well as your success in college, so invest time up front in finding good medical professionals to work with. When you visit colleges, be sure to visit their health centers. Make an appointment to meet with representatives there regarding available type 1 diabetes care. Interview the doctors, nurses, and educators.

Your parents will most likely be very helpful to you in completing this process. Don’t feel you have to rely on the school health center if better health care is available elsewhere in the area. You may want to ask your pediatrician for recommendations of endocrinologists in the area.

Discuss health insurance coverage with your parents before you leave home. You should know what your options are, how to handle emergency situations, and what your insurance requires.

More tips for college:

- Request a meeting with your parents and the Resident Assistant to go over emergency procedures. Offer to give the RA a glucagon kit to use in case you have severe low blood sugar
- Have a small refrigerator in your room for supplies and snacks. You may want to buy it yourself instead of sharing the expense with a roommate so you won’t feel guilty taking up so much of the space. Let friends know that snacks in the refrigerator are necessary for you and ask them not to help themselves without asking first
- Whatever you take for insulin reactions, have your parents buy it in bulk. That way, you won’t think twice about sticking a handful into whatever bag or coat you grab
- When you go to a party, make sure that someone you know will be there—someone who knows you have type 1 diabetes and knows what to do in case of a reaction
- If you don’t have relatives or friends nearby, have your parents network through their friends to find someone who can act as a local emergency contact if needed
- Make the decision to ALWAYS wear a Medic Alert bracelet. There are many different styles available these days
- Photocopy insurance and prescription cards, in case your wallet is lost or stolen. Your parents should keep a copy. Keep another in your dorm room
- Have two blood glucose meters, in case one malfunctions, and extra batteries
- Make sure you have a safe system for discarding needles and strips
- Keep a three-month inventory of supplies. Be sure to check periodically and call home before you start to run low. As a safeguard against running out of insulin, make sure your prescriptions are on file at a local pharmacy
- Thank your roommate ahead of time for providing support. An occasional card or small gift works wonders
- Give your roommate a “dear roommate” letter explaining type 1 diabetes and what your needs are
**Letter to the Roommate**

When you head off to school, you don't need to tell everyone you have type 1 diabetes, but some key people need to know: health services, of course; your roommate; the resident assistant (RA); and a few close friends. Here is a sample letter to a new college roommate, provided by a JDRF volunteer whose daughter has type 1 diabetes; it can also be adapted for the RA.

**Dear Roommate:**

I am letting you and a few other people around me know that I have type 1 diabetes (juvenile diabetes). Please understand that I do not want or need to be treated differently because of my diabetes, but there are some things I'd like you to know about the condition.

Usually my type 1 diabetes is under control, but sometimes my blood sugar gets too low or too high, which can endanger my health. To keep that from happening, I have to do certain things, like test my blood sugar and (wear an insulin pump/give myself insulin shots). It may help you to understand if I first tell you a little about diabetes.

First of all, please know that type 1 diabetes is not contagious. When a person eats a meal, the food is broken down into different substances, is absorbed, and enters the bloodstream. One of these substances is glucose, a sugar. The body cannot function without glucose. In turn, the body cannot use glucose without insulin, which is produced by the pancreas. My pancreas, like that of other people with type 1 diabetes, doesn't produce insulin, so I have to take insulin shots every day. It's mainly insulin, exercise, food, and stress that cause my blood sugar to go up or down.

I do not expect you to have to take care of me, but I do sometimes have low blood sugars or insulin reactions, which might confuse or scare you if you don't understand what's happening. During a reaction, for no apparent reason, you may notice any of these symptoms coming on suddenly:

- confusion
- moodiness
- irritability
- incoherence
- Shakiness
- Glassy stare

I usually know when my sugar is getting low and can avoid a reaction, but not always. If the low blood sugar persists too long, I may seem sleepy and withdrawn. At these times, I need to drink a sugared drink or eat something from my "low blood sugar food stash" right away. I may not be able to get it myself, so I would appreciate your help, even if I resist. If you don't feel comfortable with that, please call the RA or health services to help me.

Once I have some sugar, I should seem much better within 10-15 minutes. If not, try giving me more food and call one of my contacts listed below. Low blood sugar can be life threatening to me, so my food stash is like my "medicine" and needs to be kept separate from the food we can share. Finally—and hopefully this will never happen—if you ever find me unconscious, anytime, including after partying, or if I am sleeping longer than usual and you cannot wake me, I am probably in serious danger. Please call 911.

If you feel uncomfortable about being around the shots and finger pricks, or keeping an eye open for emergencies, I'm happy to talk with you about it. My type 1 diabetes is totally familiar to me but I realize it may take a little time and experience for you to adjust. Believe it or not, in spite of all the challenges that come with diabetes, I am able to lead a pretty "normal" everyday life. Most people won't even know that I have diabetes unless I tell them. I'm sure you have lots of questions, so let's set a time to talk.

Thanks,

(Signature)

*You may also want to include a list of emergency contacts for low blood sugars*
About JDRF

• Research funding facts
About JDRF

Dedicated to Finding a Cure

The Juvenile Diabetes Research Foundation International (JDRF) is the worldwide leader in funding research to cure type 1 diabetes, an autoimmune disease that strikes children and adults suddenly and lasts a lifetime. JDRF sets the global agenda for diabetes research and is the largest charitable funder of and advocate for diabetes science worldwide.

JDRF’s mission has been constant since it was founded four decades ago: to find a cure for type 1 diabetes and its complications through the support of research. Until a cure is found, JDRF is also committed to working tirelessly to develop new and better treatments to improve the lives of people who have type 1 diabetes and keep them as healthy as possible.

Today, people with type 1 diabetes rely on insulin to manage the disease. But insulin is not a cure, nor does it prevent the possibility of the disease’s devastating effects, which can include kidney failure, blindness, heart disease, stroke, amputation, and pregnancy complications. JDRF is dedicated to finding a cure for type 1 diabetes and removing the burdens and threats that the disease carries.

A Global Leader in Type 1 Diabetes Research

JDRF funding and leadership is associated with most major scientific breakthroughs in type 1 diabetes research to date. The Foundation remains a global leader in driving type 1 diabetes science forward by funding more type 1 research than any other charity. JDRF directed nearly $101 million to such research in FY2009, bringing its total research funding to more than $1.4 billion since its founding in 1970. To ensure that it supports science with the greatest potential to produce results as soon as possible, JDRF has established a research review process that involves leading scientists from around the world, as well as lay reviewers who either have type 1 diabetes themselves or have family members with the disease.

Moving Discoveries from Bench to Bedside

JDRF is a leading catalyst for translating research advances into new treatments that can improve the lives of people with diabetes in the near term – and ultimately lead to a cure. In recent years, JDRF has driven a major increase in the number of new drugs and devices being evaluated in human clinical trials, funding more than 40 such trials in FY2009. JDRF has also helped spark new interest in type 1 diabetes science from biotechnology and major pharmaceutical companies; they will be crucial partners in bringing new therapies and cures to market.

JDRF research encompasses multiple areas, with the goal of discovering and developing new drugs and devices to cure, treat, and prevent type 1 diabetes. Areas of focus include developing immune therapies, replacing and regenerating beta cells, achieving tight glucose control, and preventing complications.

Efficiently Organized for Successful Results

JDRF is structured on a business-world model that efficiently and effectively directs resources to research aimed at finding a cure and developing new treatments as soon as possible. More than 80 percent of JDRF’s expenditures directly support research and research-related education. Because of its unwavering focus on its mission to find a cure, JDRF annually receives top rankings from independent sources that rate charitable giving. JDRF leverages its impact by partnering with academic institutions, governments, biotechnology and pharmaceutical companies, other disease organizations and foundations, and people with type 1 diabetes.

A Backbone of Dedicated and Active Volunteers

JDRF was founded in 1970 by parents of children with type 1 diabetes. Today, volunteers at JDRF’s more than 100 locations worldwide remain the driving force behind the Foundation’s success in advancing research toward a cure. Because of their personal connection to type 1 diabetes, JDRF’s volunteers have a passionate and unrelenting commitment to the JDRF mission.
Research Funding Facts

JDRF’s mission is to find a cure for diabetes and its complications through the support of research. JDRF is also committed to developing new and better treatments that improve the lives of people with type 1 diabetes in the near term and keep them healthy while we advance toward a cure.

- Since its founding in 1970 by parents of children with type 1 diabetes, JDRF has funded more than $1.4 billion in research. In FY2009 alone, JDRF funded nearly $101 million, more than $42 million of which represented new scientific projects.
- More than 80 percent of JDRF’s expenditures directly support research and research-related education.
- In FY2009, JDRF funded research projects in 22 countries, including more than 40 human clinical trials.

JDRF’s Research Goals

JDRF is committed to aggressively following the most promising paths to cure, better treat, and prevent type 1 diabetes. We are targeting our resources on science that seeks to:

- Arrest the immune attack on the insulin-producing beta cells
- Restore or replace beta cell function
- Better control blood sugar levels
- Protect people from – or reverse – complications

FY2009 JDRF Research Funding

<table>
<thead>
<tr>
<th>Therapeutic Areas</th>
<th>Funding (Million)</th>
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<tr>
<td>Immune Therapies</td>
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<tr>
<td>Beta Cell Therapies</td>
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<tr>
<td>Glucose Control</td>
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<td>Complications Therapies</td>
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<td>Total</td>
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Therapeutic Areas

JDRF targets its research funding in four “Therapeutic Areas:”

Immune Therapies

This area focuses on ways to stop the immune system attack on the body’s insulin-producing beta cells that causes type 1 diabetes. Within this area, JDRF is prioritizing antigen-specific therapies that would reverse the immune attack in type 1 diabetes without suppressing the entire immune system.

Beta Cell Therapies

This area aims to find ways to restore the body’s ability to make insulin through the:

- Regeneration of insulin-producing beta cells (i.e. triggering the body to re-grow beta cells) and
- Replacement of the beta cells lost to diabetes

JDRF is prioritizing regeneration because of its potential to restore beta cell function in the largest number of people living with type 1 diabetes.

Glucose Control

This area seeks to identify ways to dramatically improve blood glucose control while avoiding dangerous highs and lows in people at all stages of type 1 diabetes. JDRF is prioritizing the development of a closed loop artificial pancreas, a device combining glucose monitors and insulin pumps, to enable people to achieve tight blood sugar control and reduce their risk of complications. JDRF is also prioritizing the development of novel insulins that are glucose-responsive, faster-acting, easier to use, and more effective.

Complications Therapies

This area focuses on ways to free people from the devastating long-term complications that can accompany diabetes, including diseases of the eyes, nerves, and kidneys. JDRF is prioritizing research in complications protection, or new approaches to assess risk and block complications from developing and progressing.
Resources/References
Below is a listing of published government materials and other information sources containing additional information about the topics covered in this guide.

Helping the Child Succeed: A Guide for School Personnel issued by the National Diabetes Education Program and endorsed by JDRF and many other organizations.  

Sample 504 Plan and Individualized Healthcare Plan issued by the Disability Rights Education & Defense Fund (in collaboration with the ADA). These are extremely thorough and comprehensive plans that can be tailored to meet a child's individual needs.  

Protecting Students with Disabilities issued by the U.S. Dept of Education's Office for Civil Rights. Written in a frequently-asked-questions format.  
http://www.ed.gov/about/offices/list/ocr/504faq.html

Legal Text of Section 504 of the Rehabilitation Act of 1973 posted on the OCR website.  

Legal Text of Americans with Disabilities Act of 1990 posted on the OCR website.  

The Civil Rights of Students with Hidden Disabilities issued by the OCR and posted on its website. NOTE: This is the only official document I’ve ever found which specifically recognizes “diabetes” as a medical condition that meets the eligibility criteria of “disabled.” As such, it becomes very useful when a school tells a family that diabetes isn’t a condition eligible for Section 504.  
http://www.ed.gov/about/offices/list/ocr/docs/hq5269.html

What is “Free, Appropriate Public Education”? issued by OCR.  
http://www.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

Listing of U.S. Department of Education’s OCR Regional Offices  

OCR Listing of Parental Advocacy Resources  
http://www.ed.gov/parents/needs/rights/ocr/parents2.html

OCR Online Grievance of Non-Compliance/Discrimination Complaint Form  
http://www.ed.gov/about/offices/list/ocr/complaintintro.html

Clarification on the Process of Delegating in the School Setting position statement issued by the National Association of School Nurses (NASN) adopted 9/15/05.  
http://www.nasn.org/Portals/0/statements/consensusdelegation.pdf

School Nurse Role in Care and Management of the Child with Diabetes in the School Setting reissued and adopted by NASN in June 2006.  

Caring for Diabetic Children in the Classroom position statement issued by the American Federation of Teachers, as well as related printed materials.  
http://www.aft.org/topics/diabetes/index.html

http://www.pta.org/archive_article_details_1152136026718.html

Diabetes and the School Setting, American School Health Association.  
Health In Action: www.ashaweb.org

Contact: MO Dept. of Health & Senior Services; Division of CDC and Health Promotion Box 750, Jefferson City, MO 65102 (573) 522-2861


Type 1 Diabetes in School, Juvenile Diabetes Research Foundation.  
http://www.jdrf.org/index.cfm?page_id=103439
School Discrimination, American Diabetes Association
www.diabetes.org/advocacy-and-legalresources/discrimination/school.jsp

Sample Section 504 Plan, Disability Rights Education and Defense Fund.

Resolution-Recognition and Care of School-Age Children with Diabetes, National Parent Teacher Association.
www.pta.org/archive_article_details_1152136026718.html

www.ed.gov/about/offices/list/ocr/docs/hq9805.html

www.ed.gov/about/offices/list/ocr/docs/howto.html

Legal Rights of Students with Diabetes, James Rapp, Arent Shereen, Brian Dimmick, Brystal Jackson.
www.diabetes.org/advocacy-and-legalresources/attorneymaterials/legalrights.jsp

http://care.diabetesjournals.org/cgi/content/full/29/suppl_l/s49

Care of Children and Adolescents with Type 1 Diabetes, Diabetes Care Journal.
http://care.diabetesjournals.org/cgi/content/full/28/1/186

Sample 504 Plan by Age and Insulin Therapy, Children with Diabetes.
http://www.childrenwithdiabetes.com/504/

College Entrance Exams
Children with Diabetes. Sample Collection of Letters & Forms for SAT and ACT accommodations.
http://www.childrenwithdiabetes.com/504/

Type 1 Diabetes in College, Juvenile Diabetes Research Foundation.
http://www.jdrf.org/index.cfm?page_id=103581

For Parents & Kids: For Schools, American Diabetes Association.

For School: Tips for Teachers, American Diabetes Association.

For Schools: Diabetes Management at School, American Diabetes Association.

For Schools: Roles & Responsibilities, American Diabetes Association.


http://www.diabetes.org/espanol/diabetes-y-la-legislacion.jsp

Diabetes at School, Children with Diabetes.
http://www.childrenwithdiabetes.com/d_0q_000.html

States with Special Laws: School Legislative Efforts, American Diabetes Association.
Appendix I: Laws That Apply to Children with Diabetes

- What laws apply to what settings?
- The three laws

- What to do when there is a problem
- Sample 504 Plan
What Laws Apply to What Settings?

<table>
<thead>
<tr>
<th>Setting</th>
<th>Section 504</th>
<th>ADA</th>
<th>IDEA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public school</td>
<td>Yes (if receiving federal funding)</td>
<td>Yes</td>
<td>Yes, if the student qualifies for special education or related services.</td>
</tr>
<tr>
<td></td>
<td>No (if not receiving federal funding)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private school</td>
<td>Yes (if receiving federal funding)</td>
<td>Yes</td>
<td>Yes. If the local school district determines that the child is eligible for IDEA, then the local school district (LEA) must provide a proportionate share of equitable services.¹</td>
</tr>
<tr>
<td></td>
<td>No (if not receiving federal funding)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious operated school</td>
<td>No</td>
<td>No</td>
<td>Yes. If the local school district determines that the child is eligible for IDEA, then the local school district (LEA) must provide a proportionate share of equitable services.¹</td>
</tr>
<tr>
<td>Private day care</td>
<td>Yes (if receiving federal funding)</td>
<td>Yes</td>
<td>If the private day care provides only day care services, the answer is no. If the private day care is providing elementary education, then IDEA will apply if the child qualifies.</td>
</tr>
<tr>
<td></td>
<td>No (if not receiving federal funding)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious operated day care</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

- Section 504 refers to Section 504 of the Rehabilitation Act of 1973
- ADA refers to Americans with Disabilities Act of 1990, and the ADA Amendments Act of 2008 (passed 9/25/08, effective 1/1/09)
- IDEA refers to the Individuals with Disabilities Education Act (enacted in 1990, reauthorized in 1997), and the IDEA Improvement Act of 2004.

¹ Under IDEA, children with disabilities who attend private schools do not have an individual entitlement to services they would receive if they were enrolled in a public school. Instead, the local school district (LEA) is required to spend a proportionate amount of IDEA funds to provide equitable services to these children.

Disclaimer: This chart and the remaining contents of this Appendix are not intended to be legal advice and should not be construed as such. They are, rather, a general guideline of the laws that apply to most schools and child care centers. A family would be well advised to look into the particular circumstances of their school if they encounter a problem.
The Three Laws

1. Americans with Disabilities Act (ADA) of 1990 and the ADA Amendments Act of 2008,

2. Section 504 of the Rehabilitation Act of 1973 (Section 504)

3. Individuals with Disabilities Education Act (IDEA)

**LAW #1 - ADA (The Americans with Disabilities Act)**

The ADA is an anti-discrimination law and applies to all public entities (including public schools, private school, day-care centers, etc.) except those operated by a religious entity. The purposes of the Americans with Disabilities Act that apply to individuals with diabetes are, “(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities,” and “(2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities.”

The ADA also states that no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. This means children with diabetes (or other disability) must be given an equal opportunity to participate at school and cannot be excluded from any equal access academic programs or school sponsored extracurricular activities, field trips, etc.

Schools and other public entities (e.g. day-care centers) are required to make reasonable modifications to policies, practices, and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the service, program, or activity being provided — or is an undue hardship (meaning an action requiring significant difficulty or expense.)

**ADA defines the term disability as follows:**

“The term ‘disability’ means, with respect to an individual (A) a physical or mental impairment that substantially limits one or more of the major life activities* of such individual; (B) a record of such an impairment; or (C) being regarded as having such impairment….”

“The ADAAA (ADA Amendments Act of 2008) adds to the ADA a definition of “major life activity” that includes, but is not limited to, “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating and working.” The ADAAA also defines a “major life activity” to include “major bodily functions,” which include, but are not limited to, “functions of the immune system, normal cell growth, digestive, bowel, bladder, neurological, brain, respiratory, circulatory, endocrine and reproductive functions.”

Newly passed Amendments to ADA went into effect on January 1, 2009. Sections of the newly passed Amendments state that, 1] major life activities now specifically include the “endocrine system,” 2] mitigating measures such as the use of medicine, medical supplies, or medical equipment shall not be considered in determining whether the person is disabled. In other words, a person with diabetes who uses insulin or and an insulin pump (or other device) to reduce the impact of his or her disease is still considered disabled and protected by the law. 3] "emphasizes that the definition of ‘disability’ should be interpreted broadly.” These newly passed Amendments help to clarify that people with diabetes are covered under ADA (and Section 504, as well.). For more detailed information on the ADA Amendments that went into effect on January 1, 2009, go to [http://www.ed.gov/policy/rights/guid/ocr/disability.html](http://www.ed.gov/policy/rights/guid/ocr/disability.html).

**Eligibility**

There is no formal process (no strict due process procedure) for a person/student with Type 1 diabetes to follow to be declared as, “eligible” as a disabled person under ADA. However, if a problem occurs in a school setting and a child with diabetes is not receiving appropriate services, a family should try to educate school personnel and negotiate with school personnel to obtain the necessary services. If these measures fail, a complaint can be filed alleging discrimination under ADA.
Questions about ADA?
The U.S. Department of Justice answers questions about the ADA and provides free publications by mail and fax through its ADA Information Line [800-514-0301 (Voice) 800-514-0383 (TDD)] and on its ADA Home Page on the Internet at http://www.ada.gov/. The ADA Information Line provides answers to general and technical questions, on Monday thru Friday from 10:00 a.m. until 6:00 p.m. except Thursdays when the hours are from 1:00 p.m. until 6:00 p.m. (Eastern Time). You may also order regulations and other free materials for mail delivery 24 hours a day. ADA Information by Fax provides many ADA publications that can sent directly to your fax machine. To order, call the ADA Information Line at any time and follow the fax-back system directions.

LAW #2 - Section 504 of the Rehabilitation Act of 1973

Section 504 is also an anti-discrimination law. The purpose of this law is to “eliminate discrimination on the basis of handicap in any program or activity receiving Federal financial assistance.” This would include public or private schools who accept federal funding. The Law requires that, for an eligible student, a free and appropriate public education must be provided. An educational program must be provided that is equal to that provided for non-disabled peers. Related aids and healthcare services must be provided, the program must be provided in the least restrictive manner, and reasonable accommodations must be provided. Students are required to have the same educational opportunities as non-disabled students, including participation in field trips and extra-curricular activities. The law provides that a school evaluate and determine whether the student is eligible, document the findings, and periodically reevaluate the student’s eligibility.

Note: The law says that the child must receive the accommodations agreed to but does not specifically state that the plan must be in writing. That being said, it certainly would be best practice (and common sense) to put the plan in writing. A written plan is the only way that a school can document that it is providing all of the accommodations agreed to. Not having the plan in writing could easily be cause for a complaint and a violation of Section 504. As one of the representatives from the Department of Education Office of Civil Rights (OCR) stated, “OCR would have no concept how a district/school would prove a 504 Plan exists and the accommodations being made without the Plan being in writing.”

Section 504 also applies to day-care programs. “A recipient…that provides preschool education or day care or adult education may not, on the basis of handicap, exclude qualified handicapped persons and shall take into account the needs of such persons in determining the aid, benefits, or services to be provided.”

Eligibility

A process exists for a student to be declared eligible under Section 504 and for a 504 Plan to be developed that formally and legally describes what accommodations a child with disability will receive. Section 504 eligibility is not automatic but is made on an individual basis. A team of people knowledgeable about the student must convene and determine eligibility. Although there is nothing in the law that specifically requires parents to be invited to this meeting, parents are certainly knowledgeable about the child, and it would be logical to assume that they should be invited to the meeting. Parents should be sure to make themselves available for this meeting, as the meeting can go forth if parents are invited but do not attend. Since Section 504 uses the same definition of disability as does ADA, eligibility for Section 504 and a 504 Plan should be the result. The 504 eligibility process doesn’t require the student to take or pass any particular test to be found eligible. However, the student’s academic record and teacher recommendations are among the sources to be considered by the team.

Note: Health plans are not a substitute for a 504 Plan. A 504 Plan provides a framework for the overall accommodations/modifications that a child with diabetes needs in the school setting. A health plan gives specifics of what to do when a health issue arises. For example, a 504 Plan gives the right to attend a field trip or to not take a test with high blood sugar, while the health plan covers the particulars of how many carbohydrates are to be eaten for lunch, how many units of insulin are to be given at what time, what to do in a medical emergency, etc.

Note: It is of utmost importance that a request to initiate a meeting to determine eligibility for 504, to request modifications to an existing plan, to document grievances of non-compliance, expressions of gratitude, etc. be in written form!
Questions about Section 504?

Information on Section 504 is located on the internet at http://www.ed.gov/about/offices/list/ocr/docs/placpub.html. The Office for Civil Rights (OCR) in the U.S. Department of Education (ED) enforces Section 504 of the Rehabilitation Act of 1973 in programs and activities that receive assistance from ED. OCR also enforces Title II of the Americans with Disabilities Act of 1990 (ADA), which is applicable to state and local governments.

A sample 504 Plan is provided at the conclusion of this document.

LAW #3 IDEA (The Individuals with Disabilities Education Act)

IDEA is a law that governs how states and public agencies provide early intervention, special education and related services. The Individuals with Disabilities Education Act (IDEA) requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs. If a child is determined to be eligible, IDEA requires public school systems to develop an appropriate Individualized Education Plan (IEP’s) for the child. The specific special education and related services outlined in each IEP reflect the individualized needs of each student. Specialized services are then provided for a student by specially trained/certified special education staff.

IDEA also mandates that particular procedures be followed in the development of the IEP. Each student’s IEP must be developed by a team of knowledgeable persons and must be reviewed at least annually. The team includes the child’s teacher; the parents; the child, subject to certain limited exceptions if determined appropriate; an agency representative who is qualified to provide or supervise the provision of special education; and other individuals at the parents’ or agency’s discretion.

Eligibility

For children with diabetes attending a public school, the school district is required to determine eligibility for IDEA, if requested to do so. For children with diabetes attending a private school (including a religious school), the local school district is also required to identify and evaluate these children to determine whether they are eligible for IDEA. The process involves obtaining parental consent for testing to take place, testing for a variety of potential disabilities including: processing difficulties, emotional disabilities, and other potential disabilities, as well as IQ testing. Eligibility is determined by the team, which looks at significant discrepancies between abilities and performance as well as other factors that significantly impact a student’s ability to learn. IDEA is an education act (and sometimes known as Special Education), and Section 504 is a civil rights act. In practical terms, the vast majority of diabetic students will fall under the Section 504 umbrella, the primary purpose of which is to prohibit discrimination on the basis of a disability. Most diabetic students will have no reason to be involved in the world of IDEA. There are only two reasons a student with diabetes might be eligible for IDEA. 1] the impact of diabetes is so great that the student’s learning is severely impacted (which might qualify the diabetic child for special education services under the other health impaired category), or 2] the diabetic child has an additional disability (most likely not related in any way with diabetes) that demands an individualized education plan (IEP), e.g. learning disability, mental retardation, autism, emotional disturbance, etc. If it is determined that a child with diabetes is eligible for an IEP, then this IEP would include all necessary modifications, and a 504 Plan would not be necessary.

Questions about IDEA

What To Do When There is a Problem

Most schools are cooperative and do a fine job in addressing and meeting the needs of a student who has diabetes. When there is a problem, follow these steps.

Note: Most schools have teachers, administrators, nurses, etc. who love children and will do whatever they can to make any child successful – including a child with diabetes. Most schools do a good job most of the time and make a good-faith effort to provide the needed accommodations/modifications necessary and will happily provide a 504 Plan and the services necessary for the child to actively participate in all of the school activities. However, parents are strongly encouraged, just in case there is school resistance, to document everything. Put a request for 504 Plan, a request for modifications to an existing plan, any grievances for non-compliance, any expressions of gratitude in writing; document the dates of meetings, who attended the meetings, what was decided in the meetings, etc. Parents should receive and keep copies of any paperwork generated from these meetings.

**Step 1:** Try one more time at the school level. Try to have a one-on-one, heart-to-heart with the school principal. Acknowledge that school people are busy and working hard. Be nice, be respectful, be reasonable. Remember that the goal is to obtain assistance and the accommodations/modifications needed for your child to be successful. If the school is making a good-faith effort to provide for the needs of your child and a problem still occurs, be a good parent and help out. After helping out, work with school personnel to come to a mutual understanding and agreement on how to address similar issues in the future.

**Step 2:** Section 504 law requires a recipient (a school) that employs fifteen or more persons to designate at least one person to coordinate its efforts to comply with the law. In most school districts this is the Special Education Director/Coordinator. This administrator is usually more knowledgeable about Section 504, ADA, and IDEA laws and is more likely to work to solve the problem. Contact this person. Again, be nice, be respectful, be understanding of school limitations, and have a list of items that are on your non-negotiable list. Appeal to this person's understanding of the laws. (Note: School administrators in this position are sometimes pushed very hard by their supervisors to keep spending to a minimum. In most situations, the accommodations and services needed by students with diabetes do not cost money. Work with these people to show them that what is being requested is reasonable and will not be costly in any significant way.)

**Step 3:** Contact the school superintendent with the same attitude and issues as above.

**Step 4:** Section 504 law requires a recipient that employs fifteen or more persons to adopt grievance procedures that incorporate appropriate due process standards and that provide for the prompt and equitable resolution of complaints. Put in writing a request for a due-process hearing. Address the request to the principal of the school and copy the Coordinator for Section 504 (described in Step 2 above), and the superintendent of schools, (and your attorney if you have one at this point.)

**Step 5:** Contact an appropriate person at the state department of education. Be prepared with any documentation you have (request for a 504 meeting, dates of any meetings, paperwork from these meetings) along with your non-negotiable list. Based on the advice of this agency, filing a formal complaint may be the next step.

**Step 6:** Obtain the services of an attorney and file for a due process hearing AND/OR

Contact the regional office of the Department of Education Office of Civil Rights for your state. A list showing regional offices of the Department of Education Office of Civil Rights is available at [http://www.ed.gov/about/offices/list/ocr/addresses.html](http://www.ed.gov/about/offices/list/ocr/addresses.html). Other information concerning filing a complaint can be found on the internet at [http://www.ed.gov/about/offices/list/ocr/index.html](http://www.ed.gov/about/offices/list/ocr/index.html). Based on the advice of this agency, filing a formal complaint may be the next step.
Sample 504 Plan

NOTE: This sample 504 Plan lists a broad range of services and accommodations that might be needed by a child with diabetes in school. The plan should be individualized to meet the needs, abilities, and medical condition of each student and should include only those items in the sample that are relevant to the individual student. The items listed below are brief ideas for possible modifications/accommodations. Many will need more detail and clarity to be included in any final version of a 504 Plan. All items in a 504 Plan should be clearly written with no ambiguity about meaning. Some students will need additional services and accommodations that have not been included in this sample plan. Additional sample 504 Plans can be found on the Internet.

Student’s Name________________________________ has type 1 diabetes and is eligible for a 504 Plan. Meeting to determine eligibility was held on __________________ and attended by the following people:

<table>
<thead>
<tr>
<th>Person/Position</th>
<th>Person/Position</th>
<th>Person/Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person/Position</td>
<td>Person/Position</td>
<td>Person/Position</td>
</tr>
<tr>
<td>Person/Position</td>
<td>Person/Position</td>
<td>Person/Position</td>
</tr>
</tbody>
</table>

The following are suggested accommodations/modifications. A child’s 504 Plan should include only those that apply and should spell out the details necessary for complete understanding. For example “food to be stored in the classroom.” Detail: “Parent will provide a small box with the child’s name on it and will keep it supplied with the necessary foods/beverages. Teacher will check the box once a week and notify parent if supplies need to be replenished.”

- Allow food to be stored/eaten in the classroom
- Allow insulin injection in classroom or nurse’s office
- Allow food to be stored in student’s locker
- Allow student to have/eat food in classrooms, on field trips, or other outside school activities
- Allow student to have a water bottle or quick access to water
- Allow student to test blood sugar level in the classroom or other school areas or to leave the classroom to go to the nurse’s office
- Allow student access to bathroom
- Allow student access to nurse’s office
- Allow student to be first in lunch/cafeteria line when necessary (as determined by student or _______)

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- Allow student to determine level of participation in strenuous physical activities without penalty. Student is to be allowed full participation in all activities unless student determines otherwise.

- Allow student to keep a cell phone on his/her person (Clearly define that the only appropriate use of the cell phone is for diabetic emergencies. At all other times, school rules for cell phone use should be followed!)

- Provide storage areas for food or equipment

- Provide additional time for academic testing situations or provide an alternative time if the student has a diabetic issue during a test

- Allow student to test blood sugar level/eat before tests (including standardized tests); allow student to take “off-the-clock” time to test blood sugar levels/eat during timed tests

- Allow student extra time for homework completion

- Provide modified homework or tests

- Provide additional academic help (and assign no penalties) after illnesses/absences/missing instruction due to diabetes issues

- Provide access to a school nurse. The school will have at least one person available at all times to assist the student as needed and without delay.

- Assure that the nurse, health aide, teachers, and other staff are appropriately trained in diabetes care and management and emergency treatment at the beginning of every school year. Other staff to include: ______________________

- Diabetes training will occur whenever student begins a class with a new staff member (e.g. quarter/semester times, long-term substitute, etc.)

- The student will be permitted to participate in all school-sponsored field trips and extracurricular activities (such as sports, clubs, and enrichment programs) without restriction and with all of the accommodations and modifications, including necessary supervision by identified school personnel, set out in this Plan. The student’s parent/guardian will not be required to accompany the student on field trips or any other school activity.

- Provide counselor or social worker services, if needed

- Allow the carrying of a minipack for diabetes supplies/food

- Cafeteria to provide carb counting/nutritional information for all food served to students

- Develop health care and emergency plans

- A plan to deal with emergencies will be developed by ___________ and attached and made a part of this plan. (e.g. disasters that require student to stay at school beyond the usual school day, including fire or other emergencies, etc.)
A system will be set up by the school so that any temporary substitute will be notified and provided appropriate information about the student.

Student will be provided with direction as to what to do if an adult in the school (e.g. substitute teacher) denies him/her the accommodations listed in this plan. (e.g. ask the substitute to call the office for permission for the student to leave the classroom with another student to go to the nurse’s office; ask a student to accompany him/her and leave the classroom to go to the nurse with no consequence for doing so, etc.).

Provide a copy of the JDRF School Advisory Toolkit to all staff members who will be working with the student. Point out the forms in the Toolkit with which staff should become familiar. Point out the forms for teachers to include in their substitute teacher folders.

School personnel will keep the student’s diabetes confidential unless the student decides to openly communicate about it with others

This plan shall be reviewed and amended, if necessary, at any time requested by the parent or the school, but not less than every three years or when a different school will be attended by the student.

If the student is not in class attendance, a tape recording of the class will be made and provided to the student.

If the student has a trained diabetes alert dog, the dog will be allowed to be with the student at all times.

Write a health plan detailing all of the medical needs of the student. (Note: it is the parents’ responsibility to provide health care instructions and to obtain the child’s physician’s signature endorsing the healthcare plan.)

Parent Responsibilities

Provide all food and diabetic supplies

Respond immediately to a request from the school for needed food and supplies

Work with the school and child to make sure that child understands that he/she is not to take advantage of the modifications/accommodations listed in this plan.

Work with the school and child to make sure that the child understands that diabetic supplies/food are not to be shared with or given to any other student.

Help out on occasion if at all possible when the school has made a good-faith effort to provide the accommodations and modifications listed in this plan but cannot do so for a particular activity.

Parent Signature ________________________________ Date____________________

School Personnel Signature ______________________________ Date____________________
Contact Information:
Call parent/guardian at numbers listed below. If unable to reach parent/guardian, call the other emergency contacts or student's health care providers listed below.

Emergency Contacts:

<table>
<thead>
<tr>
<th>Parent's/Guardian's Name</th>
<th>Home Phone Number</th>
<th>Work Phone Number</th>
<th>Cell Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent's/Guardian's Name</td>
<td>Home Phone Number</td>
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<td>Cell Phone Number</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other emergency contacts:

<table>
<thead>
<tr>
<th>Name</th>
<th>Home Phone Number</th>
<th>Work Phone Number</th>
<th>Cell Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Home Phone Number</td>
<td>Work Phone Number</td>
<td>Cell Phone Number</td>
</tr>
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<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Student’s Health Care Provider(s):

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>Phone Number</td>
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</tbody>
</table>

Additional information on 504 Plans can be found at http://www.childrenwithdiabetes.com/504/. There are a variety of age-appropriate samples on this site.
Appendix II: Accommodations for Standardized Testing

- Why should a student with type 1 diabetes request accommodations for standardized tests?
- How and when a student with type 1 diabetes should request accommodations for national standardized exams
- The SAT exam
- The ACT exam
- Sample physician’s letter
Why Should a Student with Type 1 Diabetes Request Accommodations for Standardized Tests?

A student with type 1 diabetes is eligible to request accommodations when taking standardized tests, including the PSAT, NMSQT, AP, and SAT, which are administered by the College Board, and the ACT college entrance exam, which is administered by ACT, Inc. The request for accommodations must be filed many months in advance of your planned testing date, since it often takes up to five months for complete and proper accommodation approval to be granted.

Sometimes the testing firms do not initially grant all of the accommodations requested. In this case, it may be necessary to go back to the College Board or ACT and ask them to reprocess the request. The most common reason this problem occurs is that the proper forms or paperwork were not filled out when making the request. The biggest problem seems to be the lack of a specific line on the accommodation request forms for “breaks as needed” on the SAT and “stop the clock breaks within sections” on the ACT. It is important to know how to phrase this accommodation request in order for it to be granted. Please remember that if a student with type 1 diabetes is denied the requested accommodation, the problem can be solved with a call to the testing board to see what is needed in order to meet the student’s requirements.

When applying for accommodations for standardized tests, it is important to work with school personnel; they can offer invaluable assistance in securing the medical and learning accommodations that the student with type 1 diabetes needs to succeed academically. It is also important to remember, however, that school personnel are not doctors and cannot possibly be aware of all of the medical issues that a student with type 1 diabetes deals with on a daily basis. It is therefore up to the parents and student to make sure that the proper accommodations are applied for and that all of them are approved.

Students with type 1 diabetes know that stress often causes high blood glucose levels. Stress produces adrenaline and adrenaline produces sugar. Therefore, in addition to dealing with the emotional stress that most students experience when preparing to take their college entrance exams, students with type 1 diabetes must deal with the physical and mental toll that abnormal blood sugar takes on their minds and bodies. During a standardized exam, the student with type 1 diabetes may have to correct blood sugar imbalances with either food or insulin, and he or she may need to be allotted additional time while waiting for the necessary correction to take effect. The student may need to test his or her blood glucose, have snacks during the exam, or take additional bathroom breaks. Having the proper accommodations in place will allow the extra time needed to handle all of the above without taking time away from the actual exam.

In order to address diabetes-related problems that can occur during exams, the student with type 1 diabetes needs to have “extra breaks” (five minutes long), “extended breaks” (10 minutes long), and most importantly, “breaks as needed” (which are granted as requested by the student, even if in the middle of a test section) for College Board exams, and “stop the clock breaks within sections” for the ACT exam. Please be aware that these accommodations are in addition to any accommodations that may be granted for learning disabilities, ADHD, or any other special needs. This will usually entail the student taking the test alone in a non-standard room with a separate proctor who is paid for by the College Board (SAT) or ACT, Inc.

Generally, the College Board and ACT, Inc. will try to do whatever is medically necessary to accommodate the student and grant whatever accommodations the student with type 1 diabetes normally receives in school as per his or her Section 504 Plan or IEP (Individualized Education Plan). It is important to note, however, that approval by one testing organization does not guarantee approval by the other. The Section 504 Plan or IEP must be current and must have been approved within the prior 12 months. However, it is possible to have accommodations granted without having a formal 504 Plan or IEP in place – for example, when a student is newly diagnosed with type 1 diabetes or when he/she is “home schooled.” Since type 1 diabetes is a chronic illness, all that should be needed in order to receive the proper accommodations is a statement from the student’s endocrinologist – on the physician’s letterhead and signed by the physician – stating that the student has type 1 diabetes, giving the date of diagnosis, and outlining the needed accommodations. The statement must spell out the “functional limitations” of the student as follows: it must state that the student requires “extra breaks,” “extended breaks,” and “breaks as needed” (or “stop the clock breaks within sections” in the case of ACT) during testing time so that he or she may test his or her blood glucose level, take extra bathroom breaks,
and bring a glucometer into the testing room, along with insulin for hyperglycemia and snacks for hypoglycemia. The letter should also state that the student may need to begin a test portion late or that he or she may need to wait to complete a test portion for either the blood glucose to rise if too low, or for the insulin to work if the blood glucose is too high. The physician’s statement is also needed when submitting the application through the student’s SSD (Services for Students with Disabilities) coordinator.

It’s important to request these accommodations, since it would be a shame for a student with type 1 diabetes to try to complete his or her exam while dealing with either very high or very low blood glucose levels. These problems may affect the student’s ability to think or see clearly and lead to poor test results, causing the student to choose to void his or her test scores and possibly missing college application deadlines. Accommodations need to be in place in order to prevent this from happening.

Another important thing to know is that if a student with type 1 diabetes is having a really bad blood sugar day or is sick on their test date, it is possible to postpone taking the exam – as long as the exam is rescheduled for within four calendar days of the original test date. It is also possible to delay the starting time of the exam on the original scheduled date as long as a “supervisor irregularity report” is submitted by the testing center along with the completed test. These problems do pose a bit of difficulty if the student was scheduled to have his or her own proctor, but sometimes these unavoidable circumstances do occur.

How and When a Student with Type 1 Diabetes Should Request Accommodations for National Standardized Exams

When requesting disability accommodations for the first time, whether for medical or learning disabilities, the student with type 1 diabetes needs to register for the College Board exams (SAT) or the ACT exam via mail (Note: schools – but not parents or students – may now make requests for accommodations online to the College Board). If the student chooses to take the test again, he or she may make subsequent registrations with accommodations online using his or her SSD eligibility code, which can be found on the student’s eligibility letter of approval. It is a good idea to register for the College Board exams as soon as the student enters 9th grade so that he or she may use the accommodations on the PSAT, NMSQT, AP, and SAT exams. Once approved by the College Board, the eligibility form needs to be submitted only once, as long as the student’s school verifies annually that the student continues to receive accommodations on school tests.

If the student does not want or need accommodations for the PSAT, NMSQT, or AP exams, he or she should apply for the SAT college entrance exam accommodations at least five months in advance of his or her planned testing date. An important point to note when planning to take college entrance exams with accommodations is that it takes a month or so longer to receive the student’s test scores than for exams taken without accommodations; therefore the student should schedule his or her test date with this delay in mind, especially if it is near the application deadline for the college of his or her choice.
The SAT Exam

When a student with type 1 diabetes requests accommodations for the SAT exam, the student and his or her parent need to complete the “Student Eligibility Form for Accommodations on College Board Test Based on Disability” and the “Consent Form for Request for Accommodations.” These forms must be sent with your physician’s statement to the student’s SSD coordinator for submission to the College Board. On the application for accommodations, it is imperative that the “Accommodation” section be filled out by checking “extended breaks” and “extra breaks” and by writing in “breaks as needed” in the “Other” section. Additional items to write in under the “Other” section include: juice, water, and snacks in the testing room; extra bathroom breaks; and glucometer and insulin pump or pen in the testing room. **It is the “breaks as needed” accommodation that will give the student the ability to “stop the clock” during the exam if he or she needs to do so in order to wait for his or her blood glucose to rise or fall as needed.** For more information, visit [http://professionals.collegeboard.com/testing/ssd/accommodations/breaks](http://professionals.collegeboard.com/testing/ssd/accommodations/breaks).

In all likelihood, the student with type 1 diabetes will be considered a “school-based” tester, and his or her exam will be mailed under separate cover to the student’s SSD coordinator, who will make accommodation arrangements for the exam. If the student’s high school is not a test center, then his or her SSD coordinator must either make arrangements to accommodate the student at his or her school or at another location. Having a separate proctor is the only way that the student will be able to “stop the clock.” Proctors cannot stop the clock for a large group of students taking the exam. A week before the exam is to take place, it is a good idea to contact the student’s school to make certain that he or she will indeed be testing in a room by him or herself and not grouped with numerous other students receiving different accommodations, which could prove to be very distracting for all of the students receiving separate accommodations.

Since these are national standardized exams, there are very strict guidelines regarding time allotted when administering the exams. **Remember, the accommodations must be explicitly spelled out on the student’s “Accommodation Approval Letter” or he or she will not receive them. Make sure the student’s SAT approval letter lists “breaks as needed” as part of the accommodations.**


The ACT Exam

When a student with type 1 diabetes requests accommodations for taking the ACT college entrance exam, the student and his or her parents must complete the “ACT Request for Special Testing” application. The SSD coordinator will submit this form along with a copy of the student’s physician statement. The statement must be prepared on the endocrinologist’s letterhead and be signed by the physician. It must state that the student has type 1 diabetes, give the date of diagnosis, and list the accommodations needed. It must spell out the student’s “functional limitations” by stating that he or she requires “stop the clock breaks within sections” during testing time so that the student may test his or her blood glucose level, take extra bathroom breaks, bring a glucometer into the testing room along with insulin for hyperglycemia, and bring snacks for hypoglycemia. The letter should also state that the student may need to begin a test portion late or that he or she may need to wait to complete a test portion for the blood glucose to rise if too low, or for the insulin to work if the blood glucose is too high.

When accommodations for type 1 diabetes issues are the only accommodations being requested, the “ACT Request for Special Testing” form must be completed by the student, parents, and SSD coordinator. The “Time Requested” option that must be chosen is “standard time on each test; authorization to test over multiple days.”

The student must also complete the “Other Accommodations Requested” question and fill in that he or she needs “stop the clock breaks within sections,” “extra breaks,” “extended breaks,” and “extra bathroom breaks.” The student must also request that he or she be allowed to bring the following into the testing room: a glucometer, an insulin pen or pump, and snacks including water and juice. This is the only option that truly accommodates “stop the clock breaks within sections”—which will allow the student experiencing a serious blood glucose imbalance during the exam to wait as long as needed for his or her blood sugar to rise if it is too low or for the insulin to work if blood sugar is too high. In the event the student also needs extra testing time for learning disabilities, ADHD, or other special needs in addition to accommodations for his or her type 1 diabetes, the option for “extended time on each test; authorization to test over multiple days” should be checked. When the student receives his or her Accommodation Approval Letter, make sure that “stop the clock breaks within sections” has been granted. For more information, visit http://www.act.org/aap/pdf/spectest.pdf.

A NOTE TO EDUCATORS ABOUT ACT ACCOMMODATIONS: Please be aware that students do not want to take the exam over multiple days any more than you want to take multiple days to proctor the exam. At present, “standard time on each test; authorization to test over multiple days” on the ACT application is the only option available that will accommodate “stop the clock breaks within sections” for a long-enough period of time to allow the student with type 1 diabetes to correct serious blood sugar imbalances. “Extended time on each test; authorization to test over multiple days” is the only option that the ACT has available that will accommodate “stop the clock breaks within sections” to correct serious blood sugar imbalances AND give the student with learning disabilities, ADHD, or other special needs extra testing time. “Center Testing #1; Standard Time National Testing” will allow a student with type 1 diabetes to have snacks while testing, but it will group the student with other students who have varying disabilities and who may not be on the same schedule as the student with type 1 diabetes. This option may also not allow enough time for blood sugar corrections to take place and can prove to be very distracting for the student taking the exam. As with the SAT, receipt of test results taken with disability accommodations will be delayed by four to six weeks, especially if the ACT plus Writing has been taken. For more information, go to http://www.act.org/aap/disab/opt1.html.

Please be aware that the guidelines for the College Board and ACT, Inc. testing accommodations can be used across the United States since these exams are national standardized exams. Students, please also keep in mind that these accommodations are available to you because of your disability; you should not hesitate to use them.
Sample Physician’s Letter

Dr. Alicia Romanzani  
Pediatric Endocrinology  
123 Main Street  
Anytown, USA   12345  
Telephone: 123-456-7890

Physician License #:  

June 1, 2010

To Whom It May Concern:

John Smith is a young man under my care for type 1 diabetes, diagnosed February 17, 2000. He is managed with an insulin pump and requires the following considerations during his SAT or ACT testing:

• He may need to begin a test portion late or need to wait to complete a test portion for either the blood sugar to rise (if too low) or insulin to work (if too high).

• He may require “extra breaks,” “extended breaks,” and “breaks as needed” and “stop the clock breaks within sections” during testing to monitor his blood glucose levels or to have a snack and fluids to manage hypoglycemia. He will need to take an insulin pen or pump and his glucometer into the testing room in addition to snacks, juice, and water. He may require extra bathroom breaks as well.

Should you require any additional information, please do not hesitate to contact this office.

Sincerely,

Dr. Alicia Romanzani
Contact your local JDRF chapter for more resources: