

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.



dedicated to finding a cure

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About the Author and the Goal of this Guide

Harold Wolff is the parent of a son with diabetes, Michael, who was diagnosed with Type 1 diabetes when he was 3½ years old; today (in 2007), Michael is an active and healthy twenty-eight year old. Harold taught students in grades four through twelve for the first half of his educational career. For the last sixteen years he was a principal of a middle school (grades six through eight) with 1500 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 about how parents of a child with diabetes and the school can work together to provide for 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 their 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 you know that the day-to-day disease management is intensive and the school must play an important role in this care.

The Juvenile Diabetes Research Foundation understands the importance of your child's care in the school setting. After receiving several requests from parents for help in their child's school, Outreach volunteer Lisa Shenson conducted an extensive research report. This report led us to take action and for that reason we have developed the, "School Advisory Toolkit" in conjunction with Harold Wolff and with contributions from Tamara Burns, JDRF Triangle Chapter Volunteer and mother to a child with type 1 diabetes. We hope this guide will

equip you for working with your child's school to ensure the proper diabetes care is provided and feel this guide will assist you in working with your child's school to ensure the best possible outcome for all.

This resource guide is just one of the resources within the JDRF School Advocacy Toolkit; there is also a Guide for Chapters (available through your local chapter). This guide includes more detailed information regarding specific state laws and additional resources should you feel the need to seek legal assistance. 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 *locations* from the menu.

Disclaimer

This manual does not give legal or medical advice. The JDRF staff/volunteers responsible for compiling the resources presented in this manual are not healthcare professionals, nor are they attorneys. Neither JDRF nor the staff/volunteers engage in rendering any medical or legal professional services by making this information available to you in this manual, and you should not use this manual to replace the advice of qualified medical and legal professionals. You should not make any changes in the management of Type 1 Diabetes without consulting your child's physician or other qualified medical professional.

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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.

Thank you for reaching out to the JDRF. We are here to support your family in any way we can.

COMMUNICATING WITH SCHOOLS

- A message to school staff
- A message to parents
- Scenario No. 1 – The cooperative and respectful way
- Scenario No. 2 – The adversarial way
- How to handle difficult situations that may arise

* See Disclaimer on Pages 2 and 3 of this Manual.

Communicating with Schools

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. You have every reason to expect that if you make a good faith effort to provide for the child with diabetes' needs, the parents will 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 need to take care of their child, BUT the parents can't do it all. Parents need to make a good faith effort to 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 provide for all of the school needs of their child. Parents are busy people with jobs, family responsibilities, and stresses that can sometimes be overwhelming. Now, added in the mix, is a child with diabetes. Add 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. Guilt, anxiety, and fear are only the tip of what parents feel upon bringing home their newly diagnosed child. A good night's sleep is a thing of

the past as the parental sixth sense kicks in, listening all night for warning signs that their child might be going into insulin shock.

- Carbohydrate counting and changing diets
- Learning about long and short acting insulin
- Learning to give shots or learning about the pump
- Learning to use the blood testing machine and interpret the results
- Worrying how exercise, illness, and stress affect blood sugars in the child with diabetes can affect blood sugars
- Dealing with siblings who no longer are the center of attention
- Worrying about the self-esteem of a child who suddenly is very different than other children
- Dealing with uninformed parents who don't understand diabetes and think diabetes is contagious and won't let their child play with the child with diabetes anymore
- Dealing with the anger of a child who suddenly can't live his/her life as he/she did before...

...and all this while trying to remain the calm, dependable mother and 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/her, 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 School Personnel Have of Parents

(SCHOOL STAFF SHOULD READ THIS, TOO)

You have a child with diabetes and you want him/her to have the very best school experience possible. 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.

The school has legal and moral obligations to your child, BUT the school can't do it all. The school needs to make a good faith effort to provide for your child, but after school personnel have done that, what else can they really do? Even the best and most caring schools/teachers can't magically make a nurse appear if one is not available. Schools and teachers are incredibly busy places/people 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 *your* child but the medical needs of other children as well. A teacher is responsible for creating a positive learning environment, planning for his/her lessons, delivering effective and interesting instruction, taking attendance, planning field trips, doing his/her part at the school (coaching, sponsoring clubs, supervising evening activities, etc.) continuing his/her own education, grading papers, communicating with parents, discussing student issues with counselors, providing make-up tests for students who were ill, providing extra help for

students, meeting with special education teachers to modify assignments and tests for special needs students, attending faculty meetings, completing endless 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 who learn at different rates
- adjusting instruction for students with different learning styles
- dealing with interruptions from the office
- worrying about the safety of students in the classroom (e.g. science labs)
- making sure that band and orchestra students get to their lessons on time
- making multiple decisions every minute about how to change instruction to better student understanding or how to deal with a troublesome student...

...and all this while *leaving no child behind*. The nurse, office staff, and administrators are all 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 him/her, but they can't be everywhere all the time and can't do it all. They need your cooperation and assistance and understanding of how much they do.

The Right Approach - The Cooperative and Respectful Way

It's 4-5 weeks before school is scheduled to begin. A parent calls the school and communicates to the secretary that her daughter has just been diagnosed with diabetes. The parent requests a meeting with the Principal (and *if possible*, the nurse and teacher) when it might be convenient. The parent acknowledges that she knows this is a busy time of year for school staff, but that it is important that they set up procedures for the school and parent to work together to provide for the safety of her daughter.

At the scheduled meeting: The parent acknowledges that she knows the school is a wonderful place, that everyone is busy, and that she realizes she is adding one more responsibility. The parent adds a comment on how much she appreciates what all of the people in the room will be doing for her daughter. The parent also communicates that she knows the time of the school personnel present is valuable and appreciates the time they are giving to creating a plan to provide the best and safest learning environment possible. The parent communicates that she is a busy parent with a job but knows that she, on occasion, will have to help out (e.g. chaperone a field trip or come to the school to give blood tests and/or shots). The parent provides information to help the school gain an understanding of 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 says she 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 but 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 demands in an emotional voice 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 states flatly that she is a busy mother who works and 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 - and now they hear that this child will need to be closely monitored and that low blood sugar is a *life-threatening* event. The teacher immediately 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 about this child? The "fight or flight" wiring kicks in and the principal, nurse, and teacher immediately 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. The nurse tells the parent that she is too busy and that the parent will have to come in four times per day and test the child and give her any necessary insulin shots. The teacher tells the parent that the parent must attend *all* field trips or her daughter can't go and that the school rule is no snacks/food in the classroom so the daughter may not have a snack during class time. The parent immediately responds that again, she knows her rights and she'll get a lawyer to force the School into a 504 plan or to qualify her daughter for special education under an "Other Impaired" label. The parent follows through and, unfortunately, a long-term adversarial relationship is begun.

How to Handle the Difficult Situations That May Arise

There are unexpected situations that may arise in the years your child is in school. Many of these situations may take you by surprise. Teachers, administration, rules or other things may change. These changes may cause you to jump to conclusions; however, remember that there are few basics things to do when facing a difficult situation. Below we have given you a list of some of the basics. We know that every situation is different; the list below could go on and on forever and may not address all the possibilities.

Some key things to remember with facing a difficult situation:

- Remain calm
- Gather all the facts
- Take a deep breath
- Offer a different way to handle things
- Seek support (i.e. local JDRF Chapter)

**1. Remain calm 2. Gather all the facts
3. Take a deep breath 4. Offer a different
way to handle things 5. Seek support
(i.e. 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
- Low blood sugar – Definition, Symptoms
- What to do about low blood sugar levels
- What is glucagon
- Blood glucose testing
- Insulin delivery methods
- Effects of exercise, illness, stress, and growth on blood sugar levels

* See Disclaimer on Pages 2 and 3 of this Manual.

What is Type 1 Diabetes?

(A SIMPLIFIED EXPLANATION)

Most school age children with diabetes have type 1, thus the name, “juvenile diabetes.” A healthy pancreas produces insulin, a hormone that the body uses to change food/glucose in the blood into energy. A person with type 1 diabetes is not able to produce any insulin. Without insulin, the glucose builds up in the blood (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. Eventually, if blood sugar levels are very high and are not brought down, coma and death can result.

In a person with a healthy pancreas, a “perfect balance” between food/glucose intake and insulin is maintained. When a person eats, the pancreas puts out the exact amount of insulin necessary to turn that amount of food/glucose into energy. If the person eats a lot of food/glucose, the pancreas puts out a lot of insulin. If the person eats just a little food/glucose, the pancreas puts out just a little insulin.

Since the person with type 1 diabetes is not capable of producing his/her own insulin, insulin must be put into the blood stream through shots/injections or through an insulin pump. If too much insulin is injected (or too little food is eaten), low blood sugar or hypoglycemia occurs. Hypoglycemia is the most common problem in children with diabetes. It can be very serious and requires immediate action. This is where the greatest problem lies in managing type 1 diabetes; how much insulin to inject? In a simple and perfect world, there would be an easy answer to this question (e.g. always eat a certain amount of food and inject a certain amount of insulin). However, this is not a simple and perfect world and there is *no way* to know how much

insulin to inject with 100% accuracy. Many factors influence how much insulin is needed 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 on the effectiveness of insulin. In addition, as a child grows, insulin needs change. Because determining how much insulin the body needs to “balance” the amount of food/glucose to inject is really a *best guess*, sometimes the guess is inaccurate and high or low blood sugar results.

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. Research has shown that maintaining good control of blood glucose (sugar) levels can prevent long-term complications of diabetes. **Insulin is NOT a cure for diabetes.**

What is Type 2 Diabetes?

(A SIMPLIFIED EXPLANATION)

A person with type 2 diabetes has a pancreas that makes some insulin, but the insulin is either insufficient in quantity or ineffective in its ability to stabilize blood sugar levels. Type 2's 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.

*See Disclaimer on Pages 2 and 3 of this manual.

Type 1 Diabetes Facts

Affects Young Children

Type 1 diabetes strikes children suddenly, makes them dependent on injected or pumped insulin for life, and carries the constant threat of devastating complications. While diagnosis most often occurs in childhood and adolescence, it can and does strike adults as well. 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 the causes of this process are not yet entirely understood, scientists believe that both genetic factors and environmental triggers are involved.

Needs Constant Attention

To stay alive, people with type 1 diabetes must take multiple insulin injections daily or continually infuse insulin through a pump, and test their blood sugar by pricking their fingers for blood six or more times per day. While trying to balance insulin doses with their food intake and daily activities, people with this form of diabetes 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.

Insulin Does Not Cure It

While insulin allows a person to stay alive, it does not cure diabetes nor does it prevent its eventual and devastating effects: kidney failure, blindness, nerve damage, amputations, heart attack and stroke.

Difficult to Manage

Despite rigorous attention to maintaining a meal plan, exercise regimen, and always injecting the proper amount of insulin, many other factors can adversely affect efforts to tightly control blood-sugar levels including: stress, hormonal changes, periods of growth, physical activity, medications, illness/infection, and fatigue.

Statistics and Warning Signs

- As many as 3 million Americans may have type 1 diabetes.
- Each year over 13,000 children are diagnosed with diabetes in the U.S; 35 children each and every day.
- Warning signs of type 1 diabetes include, but are not limited to: extreme thirst, frequent urination, drowsiness or lethargy, increased appetite, sudden weight loss for no reason, sudden vision changes, sugar in urine, fruity odor on breath, heavy or labored breathing, stupor or unconsciousness. These may occur suddenly.

What is it like to have juvenile diabetes?

Ask people who have juvenile diabetes. It's difficult. It's upsetting. It's life threatening. It doesn't go 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."

—Actress Mary Tyler Moore, JDRF's International Chairman

"Diabetes is always there. There's never a vacation. It's like a bad dream that lasts all day, all year, for my entire life."

—Patrick Finan, 16, New York

"Every day, I have to endure up to six injections of insulin and more than ten finger pricks to keep me alive. When my blood sugar is high, my head hurts, I feel angry and sad, and it is hard to concentrate. When my blood sugar is low, I am dizzy, shaky, and in danger of becoming unconscious."

—Emma Melton, 16, Massachusetts

"I already have problems with my kidneys, and I take medicine every day so my kidneys won't fail. I worry about what will happen if a cure isn't found soon. I don't have time to wait."

—LaNiece Evans-Scott, 11, Ohio

Diabetes Control & Management

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. For these reasons, it's important that children with diabetes stick to their scheduled blood check, insulin injection, and snack times. Even small deviations from their diabetes care plan schedule can cause fluctuation in blood glucose levels.

Treating Diabetes

The goals of diabetes treatment in children are:

- Maintain normal growth and development
- Keep blood sugar levels within a target range (not too high, not too low)
- Promote healthy emotional well-being

Diabetes management has changed considerably in recent years. Today, diabetes treatment plans are geared toward the needs of the individual child and their family. Efforts to maintain blood sugar levels in a target range involve balancing insulin, food intake and exercise.

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

- Eating reasonably, consistently and on schedule
- Testing blood sugar levels regularly
- Adjusting insulin as blood sugar levels and activities warrant
- Exercising regularly

High Blood Sugar – Definition, Symptoms

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

- *Best guess* insulin amount is not enough
- Eating more food than normal
- Eating a meal earlier than normal
- Eating higher glucose content food without injecting additional insulin
- Using ineffective or expired insulin
- Injecting insulin at a site on the body where the absorption rate is slower
- Missing an insulin dose
- A clog in the insulin pump tubing,
- Less exercise than normal
- Stress
- Illness or injury
- Other hormones
- Medications

High blood sugar generally does not put the person with diabetes in immediate danger. High blood sugar levels over long periods of time can lead to serious complications such as heart disease, blindness, kidney failure, and amputations.

However, very high blood glucose levels can lead to diabetic ketoacidosis (“DKA”), or a “diabetic coma.” Diabetic Ketoacidosis (“DKA”) occurs when the cells can’t get the energy they need from glucose. They begin burning fat and other body tissues for energy. This causes the release of byproducts, called ketones. Small amounts of ketones are probably not harmful, but the fat burning that occurs when there’s no insulin can cause dangerous levels of ketones. Ketones become like poison to the body. They build up in the blood and spill over into urine. Symptoms of diabetic ketoacidosis appear when there are too many ketones in the blood.

Again, in that perfect world we would all like, every person with diabetes would exhibit the exact same symptoms telling us that his/her blood sugar is high. Unfortunately, each person with diabetes is a little different and symptoms vary. The following is a list of symptoms that indicate high blood sugar. A person with diabetes may exhibit one or more of these 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 (adversely affecting academic performance)
- Weight loss (a longer term symptom) that eventually leads to coma
- _____ Other
(provided by parent or MD)

*See Disclaimer on Pages 2 and 3 of this manual.

What to do About High Blood Sugar Levels

High blood sugar is indicated when a blood test meter reading is within the range suggested by the student's physician. How high above this range will determine the actions that should be taken. The following recommendations are *general* treatments for high blood sugar. Specific actions, especially in terms of giving additional insulin, should be determined by the student's physician or parents.

1. If blood tests results are very slightly above _____

- 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 _____

- No strenuous exercise
- Drink water or sugar free drinks
- 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 _____

- No strenuous exercise
- Drink water or sugar free drinks
- Additional insulin (by chart or by instructions from physician or parent)
- Ketone test if advised by physician or parent
- If student has high ketones, contact parent
- 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**

**See Disclaimer on Pages 2 and 3 of this manual.*

Low Blood Sugar – Definition, Symptoms

Low blood sugar (hypoglycemia) is the most common and most dangerous condition that a school typically needs to deal with in children with diabetes. If blood sugar levels get low enough, insulin shock occurs. This is a potentially life-threatening condition if not treated promptly. 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:

- Best guess insulin amount is too much
- Eating less food than expected
- Eating a meal later than normal
- Injecting insulin at a site on the body where the absorption rate is faster than usual
- Forgetting that insulin dose was already administered and injecting a second time
- More exercise than normal
- Illness or injury
- Other hormones
- Medication interaction

In a perfect world, every person with diabetes would exhibit the exact same symptoms telling us that his/her blood sugar is low. Unfortunately, each person with diabetes unique and symptoms vary. The following is a list of *general* symptoms that indicate low blood sugar. The person with diabetes may exhibit one or more of these symptoms.

Mild to Moderate Symptoms

- Dizziness
- Nervousness
- Personality change
- Blurry vision
- Shakiness
- Nausea
- Crying
- Sluggishness
- Pale coloration
- Irrational behavior
- Sweating
- Poor coordination
- Hunger
- Confusion
- Headache
- Light headed
- Irritability
- Drowsiness
- Erratic response to questions
- Inability to concentrate
- _____ Other
(provided by parent or MD)

Severe Symptoms

- Symptoms as listed to the left
- Convulsions
- Unconsciousness
- _____ Other
(provided by parent or MD)

*See Disclaimer on Pages 2 and 3 of this manual.

What to do About Low Blood Sugar Levels

Low blood sugar is indicated when a blood test meter reading is below the target range specified by student's physician. How far below that target range will determine the actions that should be taken. The following recommendations are *general* treatments for low blood sugar. The student with diabetes' physician and parents should determine specific actions. *It should be noted that people with diabetes demonstrate symptoms of low blood sugar at various readings. Some students with diabetes feel perfectly fine at readings slightly below 70. Some diabetics begin to show low blood sugar symptoms at readings somewhat above 70.*

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 to within target range; may need an additional snack sometime later in day
- Any other time – eat a snack; after eating, student should test again to make sure blood sugars levels are back to within target range; may need an additional snack sometime later in the day
- Continue to monitor student by testing regularly to see if blood sugar comes up

2. If blood tests results are low and student is showing signs of low blood sugar but is still 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 to 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
- Remain calm
- Call 911
- *NEVER administer food or drink to an unconscious person, as it may obstruct the airway*
- Administer emergency glucagon shot (unconsciousness may last up to ten minutes post-glucagon, be prepared for vomiting as the student comes out of consciousness)
- Call the student's parents after administering glucagon
- Direct monitoring of student by nurse or trained personnel until blood sugar levels return to target range
- Additional food when student is able (e.g. crackers) if needed to keep blood sugar levels in target range

*See Disclaimer on Pages 2 and 3 of this manual.

What is Glucagon

Glucagon is used to raise the blood sugar when a person with diabetes is unable to take liquid or food by mouth because of severe sleepiness, unconsciousness, or seizure activity. Glucagon must be injected with a syringe into the skin, like insulin. It is a hormone, which helps the liver to release glucose to raise the blood sugar levels.

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 health care professional for additional explanation, if necessary.

Glucagon should not be mixed after the expiration date printed on the kit and on one vial. Check the date regularly and replace the medicine before it expires. The printed expiration date does not apply after mixing, *when any unused portion must be discarded.*

The printed expiration date does not apply after mixing, when any unused portion must be discarded.

Blood Glucose Testing

People with diabetes have to check their blood glucose levels throughout the day using a blood glucose meter. The meter tells them how much sugar (glucose) is in their bloods at that particular moment, and based upon the reading they take insulin, eat, or modify activity to maintain blood sugars within their target range. Regular testing of blood sugar levels is an essential part of diabetes care. Testing is done by taking a drop of blood, usually from a finger, and placing it on a special test strip in a glucose meter. Blood sugar meters are easy to use and most children quickly learn how to do their own blood sugar tests. Diabetes healthcare professionals frequently recommend that children test their blood sugar levels several times during the school day (for example, 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 is rarely possible in children with diabetes. A healthcare provider will often identify a target range for blood sugar levels, for example, 80-180 mg/dL.

However, maintaining blood sugar levels within the target range cannot always be accomplished, no matter how hard one tries. Children'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. *It's important that children are never made to feel that it's their fault if their blood sugar is out of range.*

The Latest Technology in Blood Glucose Testing

As of 2006, a new technology device has come on the diabetes management scene; this device is called a Continuous Glucose monitoring system. This device works much like an insulin pump and displays on a screen the individual's blood glucose level constantly. This system will still require a few finger pokes in a day but should drastically reduce the number of "meter" tests in a child's school day. Because the device has a site much like a pump it is important that the site is changed at least every 3-5 days.

It's important that children are never made to feel that it's their fault if their blood sugar is out of range.

**See Disclaimer on Pages 2 and 3 of this manual.*

Insulin Delivery Methods

Syringes, pens, and pumps; they all do the same thing – deliver insulin. These items deliver insulin into the tissue so the body can use what it doesn't produce on its own.

Insulin Injections

Some children manage diabetes with 2 to 3 insulin injections per day. However, the number of injections needed varies from child to child. Insulin injections typically are administered at regularly scheduled times a day. There is no strict rule about the age at which children should be able to administer their own injections. Some inject via syringes while others may use an insulin pen. Both really do the same thing; however, the pen can be more convenient when children need a single kind of insulin. Also some children find the pen needles more comfortable than the syringe needle.

Insulin Pumps

An alternative to insulin injections is the insulin pump, which delivers a continuous low dose of insulin through a cannula (a flexible plastic tube) with a small needle that is inserted through the skin into fatty tissue. The cannula is taped in place and the needle is removed. An insulin pump comes with special instructions for care and maintenance, which should be included in the Diabetes Medical Management Plan. The pump is a computerized device, about the size of a beeper or pager, which can be worn on a belt or in a pocket.

The advantages of the pump include:

- Greater flexibility of meals, exercise and daily schedule
- Improved physical and psychological well being
- Smoother control of blood glucose level

Disadvantages of the pump:

- Risk of infection
- More frequent hypoglycemia
- Ketosis and ketoacidosis (risk of very high blood sugars)
- Constant reminder of diabetes

When a student uses an insulin pump more frequent blood sugar testing may be necessary. If the testing can be done in the classroom, which would be preferred, the student will miss less classroom time. Testing can also be done in the office or clinic if necessary.

Personal Choice

The type of insulin delivery method a person with diabetes chooses to use is a very personal decision made by the child, family and medical care provider. The same method may not be the right choice for everyone.

**See Disclaimer on Pages 2 and 3 of this manual.*

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

In earlier sections on the definitions and symptoms of low and high blood sugar, it was stated that exercise, illness, stress, and growth have an impact on blood sugar levels. This is something teachers and school personnel need to recognize as they deal with the student with diabetes.

Exercise makes insulin work more effectively, i.e. it takes less insulin to balance the food intake amount. Therefore, a student who has taken his/her *usual* dose of insulin and eaten his/her normal amount of food may experience low blood sugar if he/she exercises more than usual. At school, this comes into play mostly in physical education class. The intensity level of physical education classes varies on a day-to-day basis. Sometimes students are learning the rules of a game and the physical intensity level is low. Other days, students are *playing* the game, running, or doing some other sort of more intensive physical exercise. On days like this, the physical education teacher may have the student eat more food and/or monitor the student more closely before and during the activity. In addition to physical education class, more than usual exercise for a child with diabetes can occur during recess or an outside class activity time. At the middle and high school levels, a student with diabetes participating in a sport might also need to plan for this additional activity by reducing insulin intake or by eating additional food before the activity begins.

Illness and stress can impact diabetes management by making blood sugars rise. This can affect the student's classroom performance because the student most likely doesn't feel well (see symptoms of high blood sugar in an earlier section). When a student with diabetes is ill or stressed, it may be necessary to curtail physical exertion (be excused from physical education or reduce intensity of activity). An academic teacher may find it necessary to provide extra time for a student with diabetes to do work. It may also be necessary to provide some additional time to the student to help him/her understand concepts taught in class when he/she was not able to concentrate effectively.

There are certainly times during a child's life when he/she achieves (at least for a short time) the "perfect balance" of insulin and food intake. For several months or even longer, the child can be doing great and life is good. Then the child has a growth spurt and that "perfect balance" is gone. Early adolescence can be an especially difficult time as the body not only grows, but hormones are busily turning boys and girls into men and women. When these growth times occur, low and high blood sugar issues may be more frequent, and the student may need more help – both at school and at home.

**See Disclaimer on Pages 2 and 3 of this manual.*

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 Pages 2 and 3 of this Manual.

Parent School Partnership

Establishing a partnership with your child's school is an important part to creating a supportive environment for your child while at school. 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.

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 difference between type 1 and 2 diabetes to your child's teacher. While most people know of diabetes, much of their knowledge is on type 2. The Diabetes Basics section of this manual is designed to help with the basic and more detailed education of type 1 for teachers and even school nurses. Your school nurse may or may not have had previous experience with other children with diabetes; it is important for the school nurse to understand that each person's experience with the disease is different.

In the event there is no school nurse at your school (this can be the case even in some public schools) another adult in the school, usually a teacher or administrator should be designated as the "go to person" for your child. They need to learn all they can about your child's diabetes management routine and be your child's support person during 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 regularly about your child's diabetes regimen separate from academic conferences.
- Check in regularly with the school nurse as she may be aware of other concerns.
- Check in about supplies replenishment as necessary.
- From time to time, eat lunch with your child at school to meet the lunchroom staff and monitors.
- Consider refresher training when school starts back after the New Year, as teachers change and unused information may be "compartmentalized".
- Send a holiday greeting thanking administration and all care team members for their participation and care.

An Adult & A Back-Up

An adult as well as a back-up adult should be trained to test blood glucose; know what to do if the blood glucose is out of the target range; know when and how to check for ketones, and know what to do if the child's ketone level is abnormal. An adult as well as a back-up adult should know how to recognize and treat low blood sugar (hypoglycemia) and high blood sugar (hyperglycemia) levels. If the child is mature enough to treat himself/herself, they 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 child needs an insulin injection(s) during school hours, an adult as well as a back-up adult should be trained to give the student insulin injections (and/or supervise the student as they administer their own injection).

An adult as well as a back-up adult should be trained to give a glucagon injection.

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).

- An adult as well as a back-up adult should know the child's meal plan and work with the parent to coordinate it with the schedule of the other children in the class, if possible. They should also notify the parents whenever special events come up that might affect the meal plan

- All adults who have responsibility for the immediate custodial supervision or care of your child at school should be trained to recognize low blood sugar (hypoglycemia) and high blood sugar (hyperglycemia) and know emergency procedures
- Allow the child to see the school nurse or other school medical personnel whenever needed
- Allow the child to eat a snack anywhere and to use the restroom and drink water at any time
- Allow the child to miss school for doctor's appointments to monitor diabetes without incurring negative consequences
- Provide a safe and secure location for storage of insulin and Glucagon and allow the child immediate access to diabetes supplies at any time
- Ensure the child's full participation in all sports, extracurricular activities, and field trips, with any necessary supervision provided
- Provide aids to help the child 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 hypo- or hyperglycemia

Recommended Parent Responsibilities

- Inform the school/administrator that your child has diabetes
- Provide the information needed for training of school staff (samples provided in Diabetes Basics and Educate the Educator sections)
- 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 and that training may have to be done more than once
- Work with the Principal or building administrator to identify school staff (hopefully including main academic teacher) for extra training
- Provide *specific* information about your child (on the forms, attach your child's picture)
- Work with school staff to determine when and where blood testing is to take place
- Clearly communicate (verbally and written) your permission for school staff to call 911 whenever they deem it necessary and to administer glucagon – *no questions asked*
- Provide multiple emergency contact people and phone numbers including your physician
- Make sure that it is clearly communicated that the school has your permission to share the needed medical information about your child with everyone who needs to know
- Make sure you 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 - batteries and test strips to go with it
 - A ketone meter (ketone strips if you cannot get the meter)
 - 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
 - Form of protein snacks (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 advantage of modifications or accommodations provided (e.g. not trying to get out of physical education activities when he/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 age 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 he/she feels ill

- Promote, encourage, and teach your child the skills to become more and more independent in his/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 sincerely try unsuccessfully to arrange for a substitute nurse, thank them for trying so hard and then give up *your* day to go to school and provide services for your child.) Understand that, after school personnel make their best good faith effort and are unable to provide some service for your child on a temporary basis, threatening legal action or yelling at them is not appropriate behavior
- Help out at some after-school or extra-curricular 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 difference 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 extra 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 with the student 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. no disciplinary action for leaving class to come to the nurse's office if a substitute teacher says that the student cannot leave class). Remind 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, 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 (e.g. diabetes).
- 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 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 diabetes.
- Work with an interdisciplinary team to implement the Health Care Plan and Section 504 or 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 blood test 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 time.
- 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, EVER, send the student to the nurse's office without another student or adult accompanying him/her!!!
- Genuinely welcome the child into your classroom and create a supportive environment for the student with diabetes.
- 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 with diabetes needs are remembered/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/ 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.

PE Teacher & Coach

- Work with an interdisciplinary team to implement written care plans, including Section 504, IEP or other education plan and the Health Care Plan.
- Provide instruction to students for information and assignments missed due to diabetes related care.
- Develop and provide a written plan for substitute teachers and other classroom aides that details diabetes-related needs and emergency plans.
- Inform students with diabetes and their families about changes in the class schedules such as class parties, field trips, extracurricular activities and special events.
- Maintain emergency diabetes supplies.
- Allow student/athlete with diabetes to eat food or drink liquids in class or at practice/games as needed.

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 meal.
- Allow student with diabetes to eat first if low blood sugar (hypoglycemia) is present.

Bus Driver

- Know which students on their 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/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/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/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 teacher cell phone) to call the nurse's office to let him/her know that the student is on the way.

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, beginning to lose consciousness, or beginning to experience convulsions, lay the student on the floor on his/her side. This is to avoid further injury by a student falling on the floor and hitting his/her head and to avoid choking.

**See Disclaimer on Pages 2 and 3 of this manual.*

EDUCATE THE EDUCATOR: STAFF TRAINING

- Identification of staff for training
- School staff training tools/samples
- Potential academic and school rule modifications
- Emotional issues involving the student
- Extra-curricular/After hours school events
- Notification/training of substitute teachers
- Educational tools and templates

* See Disclaimer on Pages 2 and 3 of this Manual.

Educate the Educator

In caring for children with 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 not be expected to independently provide all of their own diabetes management. Thus, the education about how to care for a child and adolescent with diabetes must be a group effort of the parents, school staff, and the student with diabetes.

When a student has been newly diagnosed, it is critical that you initiate a partnership with your child's school in caring for his/her 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, the differences between type 1 and 2. Included

in this section are training tools that might assist with your school staff training and educating your child's educator.

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

- Promote a healthy, productive learning environment for students with diabetes
- Reduce absences of students with diabetes
- Reduce classroom disruption
- Help ensure effective response in case of 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(s)
- Dean(s)
- Nurse
- Guidance Counselor(s)
- Social Worker
- Psychologist
- Academic teacher(s)
- Physical Education Teacher(s)
- “Specials” teachers (music, art, etc.)
- Other teachers (speech teacher, special education teacher, reading teacher, gifted teacher)
- Police Liaison Officer
- Librarian
- Band/Orchestra/Chorus teacher
- Classroom aides
- Cafeteria manager
- Lunchroom monitors
- Hall monitors
- Bus drivers/bus driver manager
- Coach
- Play Director
- Sponsors of clubs which the student might attend
- Office secretary/aide who meets substitute teachers when they arrive
- Secretaries who sometimes help out the nurse
- Bus dispatcher (so that he/she can notify substitute drivers)

SAMPLE: 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 to provide copies of care plan
When: Shortly after contacting school to set up meeting
Familiarity with these materials 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
- Influences: Schedule (timing, activity), meals/snacks, other hormones, illness

Additional Topics:

- Request that Taking Diabetes to School be read to class, if age appropriate
- Determine how and where to perform classroom blood glucose checks

- Determine schedule strengths/weaknesses
- Discuss timing/strategies of snacks and meals
- Discuss situations requiring communication/coordination: celebrations, lessons with food, treats, birthdays, field trips, field day, delayed start, early dismissals, substitutes, nurse/Specials substitutes

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

Part 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

SAMPLE: Diabetes Care Team Meeting Talking Points

- (Child's name) has type 1 diabetes and requires insulin so her body can use the food she eats. Daily care requires a regimen of checking BG 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 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 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 other hormones and illness.
- 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. 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 him/her always. No one else should carry it or be in it.
- Her/his food is "counted", so she must finish all food given. Call if there is a spill or problem.
- If in doubt, ALWAYS call.
- If her pump alarms, 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 a 10:15 check may be necessary. Otherwise, he/she will check before snack, lunch and administer a "bolus" of insulin. She/he will also check before getting on the school bus - 3:15 seems to work well.
- 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 (Child's name) safe participation: assemblies standardized testing, celebrations, lessons with food, treats, birthdays, field trips, field day, delayed starts, early dismissals, substitutes, nurse/specials substitutes, fire drills, lock-down drills.

Thank you for your care and support!

SAMPLE: Letter for the Children's School Diabetes Care Team

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*) caring for her diabetes at school.

(*Child's name*) is very comfortable talking about her diabetes. She doesn't 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 advanced 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

page 1 of 2

Continued Sample: Letter for the Children's School Diabetes Care Team

What is Diabetes?

Diabetes is a chronic disease that impairs the body's ability to use food properly. 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.

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. 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, 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 insulin-dependent 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 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.

SAMPLE: Letter for the Child's Classmates Families

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* 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

page 1 of 2

Continued Sample: Letter for the Child's Classmates Families

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. 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 (*Mary 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 (*Mary uses fruit snacks or a juice box*).

Children **cannot** outgrow insulin-dependent 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 prevent or post-pone 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.

SAMPLE: Diabetes Management Overview for Staff/Substitutes

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. Everyday, 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*) personality, demeanor and behavior should keep in mind recognizable symptoms of low blood sugar and immediately act when symptoms are exhibited, reminding her to consider how she feels, and having 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*) 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 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, a glucagon injection must immediately be administered. (See: What is a Glucagon: on page 15 of this guide) Reading the directions for mixing and injecting glucagons ahead of time is highly recommended. These directions should be carefully followed in the case of a hypoglycemic emergency. The implementation of the above guidelines greatly reduces any possibility of such an emergency.

*See Disclaimer on Pages 2 and 3 of this manual.

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 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 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
- 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 testing situations
- 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
- Provide access to a school nurse
- Assure that the nurse and other staff are appropriately trained in diabetes care and management and emergency treatment
- Assure full participation in all school activities with necessary assistance
- Provide counselor or social worker services
- Allow the carrying of a minipack for diabetes supplies

Parent, child, 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.

**See Disclaimer on Pages 2 and 3 of this manual.*

Emotional Issues Involving the Student

Children with diabetes have lost control and independence of their bodies. There may be friends (or parents of friends) who are now afraid of “catching” the disease. All of a sudden, they can’t eat what all of their friends are eating or drink what all of their friends are drinking. After the baseball game, everyone runs to the ice chest to get a coke, but everyone is saying, “Don’t drink the *diet* coke; that’s for _____.” Most children, and especially early adolescent children, don’t like to be different. They want to be just like everyone else. The conflict between wanting to be like everyone else, and yet need to eat differently and be treated differently due to his or her diabetes needs can be emotionally troubling. Normal, early adolescent issues and the desire by children for independence can be an additional issue as children and parents conflict about diabetes management, possibly resulting in oppositional behavior. Parents and school personnel should work together to address these emotional issues.

Some children are very open about their diabetes, happily sharing the news and “educating” their fellow students. Other children will hide under their desks when they eat their snack. Once again, the age when diabetes onset begins, the age and maturity of the child, and the emotional state of the child are all factors in making decisions. A discussion with the parent, child, nurse, administrator, guidance counselor, and teachers needs to be held to determine how the child’s diabetes will be handled with other students and how the parent and school will work together to address the child’s emotional issues. It is important to note that the school is intimately involved in some of the topics listed below. Other topics may have some impact at school and the school should be aware

and involved, but the *parent* should be the primary person dealing with the issue. Decisions need to be made concerning the following topics:

- 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 go 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 child with diabetes?
- How and who will do the telling/educating?
- How will parties/food be handled so that the child with diabetes is not left out and not put in an embarrassing situation?
- Will the student wear an insulin pump during physical education class (or where it will be stored?)
- Will the child wear a medical ID bracelet?
- How will the school and/or the parent deal with the child if he/she resists care, does not take his/her insulin, refuses to check blood sugar levels, reports false glucose levels, etc.?
- If the child with diabetes manipulates his/her insulin/food intake to gain or lose weight, how will that be handled?
- If the child with diabetes attempts to show independence or rebellion by refusing insulin, food, testing, or other diabetes management, how will that be handled?
- How will depression or anger issues be handled?

Extra-Curricular/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 year-book, playing a sport, participating in intramurals, joining a club, joining the jazz 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 at any of these extra-curricular or after-hours school activities. For most of these activities, the sponsor of the activity is the natural person to be trained and available. In the case of a school dance/activity night or similar kind of activity, it would certainly be reasonable to expect that if no trained staff member can be in attendance, the parent 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 a hypoglycemia it is still critical to have them sit out for a period of time in order to recover and allow the body time to bring the blood sugar up within their 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 regards 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 for 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 most 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 substitutes 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 substitute teacher 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.

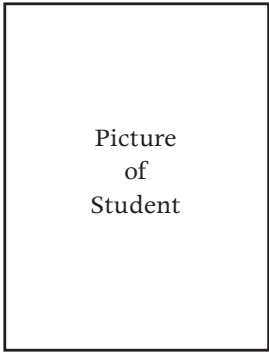
Substitute Teacher: Emergency Medical Form

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

Other *(provided by parent or physician)*

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 eat in class, go to restroom).

Field Trip Checklist

- Contact parent to discuss duration and location of field trip to determine needs
- Location of parents during field trip time period
- Cell phone
- Contact list with emergency phone numbers
- Diabetes knowledgeable chaperone
- Needed food (lunch and snack) plus extra food
- Water
- Fast acting (high sugar) liquids (e.g. orange juice, coke)
- Glucose tablets
- Glucagon
- Blood testing meter, testing strips, lancets, antiseptic wipes (gloves if student will not test independently)
- Insulin supply (if needed)
- Insulin pump and supplies (if applicable)
- _____
Other, as specified by parent or child's physician

Notes:

High Blood Sugar Help Sheet

Symptoms:

Thirst (dehydration)

Blurry vision

Increased hunger

Lethargy, drowsiness, exhaustion

Sweating

Vomiting

Frequent urination

Stomach pain

Nausea

Confusion

Fruity, sweet, or wine-like odor on breath

Inability to concentrate

Response:

1. If blood tests results are very 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 high ketones, contact parent
- 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
Light headed	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 tests 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 Numbers

1 Student's Full Name _____

2 Mother _____

Home Phone _____ Work Phone _____ Cell Phone _____

3 Father _____

Home Phone _____ Work Phone _____ Cell Phone _____

4 1st Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

5 2nd Emergency Contact _____

Home Phone _____ Work Phone _____ Cell Phone _____

6 Physician/Endocrinologist _____

Office Phone _____ Other Contact Phone _____

Hospital of Choice _____

Address _____

Phone _____

7 8 Insulin information/dosages _____

9 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
- References for those who desire more information

*See Disclaimer on Pages 2 and 3 of this Manual.

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 his/her education. While most of you will never have a problem with your school, it is still good to have a plan in place that protects your child and his/her educational services. Hopefully you and your child's school will be able to cooperatively and respectfully work together and there will never be a need to enter into an adversarial relationship.

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 as Section 504)
2. The American 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/plan that protect him/her while in the school setting.

DISCLAIMER

Indeed, 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 as of August 2007, JDRF makes no representations as to the accuracy or completeness of the information contained in this manual.

Section 504

According to this law, parents of qualifying children have the right to develop a Section 504 plan with their child's school. Schools can lose federal funding if they do not comply with this law. Any school that receives Federal funding must comply with Section 504 laws. 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 act requires schools to identify educational needs and when necessary, develop a "504" plan. A 504 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 get special accommodations when taking standardized test (e.g. PSAT, SAT and ACT). These accommodations usually include "stop the clock" breaks for blood glucose testing, bathroom visits, or taking emergency glucose to treat low blood sugars. Testing organizations (for PSAT, SAT, and ACT) generally require that students have a 504 plan on file before providing the accommodations.

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.

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 be given a "free, appropriate public education." Qualification for this depends on how diabetes affects their ability to learn. If they qualify, you have the right to develop an Individualized Education Program (IEP) with their school. An IEP is similar to a Section 504 but would include 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.

- California
- Connecticut
- Hawaii
- Kentucky
- Massachusetts
- Montana
- Nevada
- North Carolina
- Oregon
- Oklahoma
- 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.

<http://www.diabetes.org/advocacy-and-legalresources/discrimination/school/legislation.jsp>

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 for dealing with the following:

- Blood sugar monitoring, including the accommodations for testing and treating
- Assuring that there are staff members trained in checking blood glucose levels, recognizing and treating high and low blood sugar, insulin administration (including doses/injection times prescribed for specific sugar values and the storage of insulin), and glucagon administration
- Eating whenever and wherever necessary, including eating lunch at an appropriate time with enough time to finish eating
- Taking extra trips to the bathroom or water fountain
- Ensuring full participation in all sport, extra-curricular 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 materials 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 as close to the rest of the class as closely 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, extra-curricular, 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:

1. If the school, parent, and student can come to a cooperative and respectful (and hopefully even friendly) agreement regarding what should be included in a 504 plan, what services, modifications, and accommodations will be made, and the school makes a good faith effort to provide all of these services, and the parents accept the good faith effort of the school and provide parental support on the rare occasions that the school's good faith effort doesn't work, then there is no need for any further action.
2. If the school, parent, and student cannot come to this kind of agreement, and there is mistrust on the parent's part that the school is providing all that it should, the parent should formally (in writing) request that a 504 meeting occur and a 504 plan be put into place. It is suggested that before the 504 meeting, the parent research and study sample 504 plans (see Educate the Educator section) and come to the meeting prepared to provide the specific modifications and accommodations that the parent believes are necessary for their child to be successful in the school environment. The parent also need to know that they have the right to bring a friend, advocate, or lawyer to the 504 meeting to assist in the discussion and decisions that will be made.
3. On rare occasions, the student's academic performance may be so adversely affected by diabetes complications that a student's needs may be better served by receiving special education services. If a parent believes this to be the case, the parent should 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 be determined to be eligible (meet certain criteria) for special education services. If determined to be eligible, an IEP (individualized education plan) is written and specially certified teachers (special education teacher) become involved in the education of the child.

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

References for Those Who Desire More Information

A great deal of information about schools and student 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.

- 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. Available at <http://www.ndep.nih.gov/resources/school.htm>
- Juvenile Diabetes Research Foundation www.jdrf.org
(*Look at the life with diabetes 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

* See Disclaimer on Pages 2 and 3 of this Manual.

Diabetes in the Day Care Setting

First and foremost, remember the laws just discussed in the previous sections apply to the parent with a child in daycare as much as they do for a school aged child. Day care centers (with the exception of religious affiliations) cannot deny accepting your child, not only because it's wrong but because many of them do receive federal funding through Head Start or other child development government programs. Under these laws, diabetes has been determined to be 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 diabetes.

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.

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. At the postsecondary level, on the other hand, colleges have no responsibility to identify 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.

As parents, you may want to inquire about special accommodations while exploring colleges with your teen in order to help guide his/her decision based on your teen's 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 in the accommodation plan 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.

For the Student: Going Away From Home - JDRF.org Resources

Going away to college can be scary, especially if it's your first real foray into working with type 1 diabetes (juvenile 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 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 – JDRF.org Resources

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; also, 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 is the world's largest charitable funder and advocate of type 1 diabetes research. The mission of JDRF is to find a cure for diabetes and its complications through the support of research. Type 1 diabetes is a disease, which strikes in childhood, adolescence, or adulthood, but lasts a lifetime. It requires multiple injections of insulin daily or a continuous infusion of insulin through a pump. Insulin, however, is not a cure for diabetes, nor does it prevent its eventual and devastating complications, which may include kidney failure, blindness, heart disease, stroke, and amputation.

Building Upon Research Successes

JDRF funding and leadership is associated with most major scientific breakthroughs in type 1 diabetes research to date. In fact, JDRF funds a major portion of all type 1 diabetes research worldwide, more than any other charity. JDRF provided more than \$122 million to diabetes research in FY2006, and is responsible for more than \$1 billion in direct funding since it was founded. Our research review process not only includes leading research scientists from around the world, but lay reviewers who either have type 1 diabetes or have family members with type 1 diabetes, ensuring that JDRF funds research with the greatest impact throughout the world, leading to results as soon as possible.

Moving Research from Bench to Bedside

JDRF is driven to be a leading catalyst for development science that delivers therapeutics to improve the lives of people with diabetes in the near term, ultimately leading to a cure. Working toward this

goal, JDRF has taken the lead in translating basic research breakthroughs into cure therapies in such areas as restoring autoimmunity, preventing and reversing complications, islet replacement, beta cell regeneration, and achieving metabolic control. The Foundation creates multidisciplinary programs that bring together diabetes researchers from both academic institutions and industry to find a cure for diabetes and its 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 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 research impact by partnering with and stimulating increased research spending on the part of public and private medical organizations and other entities throughout the world.

A Backbone of Dedicated and Active Volunteers

JDRF was founded in 1970 by the parents of children with type 1 diabetes. As a result, JDRF volunteers have a personal connection to type 1 diabetes, which translates into an unrelenting commitment to finding a cure. These volunteers are the driving force behind more than 100 locations worldwide that raise money and advocate for government spending for type 1 diabetes research.

Research Funding Facts

Since its founding in 1970 by parents of children with type 1 diabetes, JDRF has awarded more than \$1 billion to diabetes research, including more than \$122 million in FY2006. More than 80 percent of JDRF's expenditures directly support research and research-related education. In FY2006, the Foundation funded more than 500 centers, grants, and fellowships in 20 countries.

Areas of Scientific Investigation

- Artificial Pancreas
- Beta Cell Development
- Beta Cell Function
- Beta Cell Regeneration
- Clinical Trials
- Environmental Triggers
- Gene Therapy
- Genetics
- Hypoglycemia
- Immunology
- Islet Transplantation
- Nephropathy
- Neuropathy
- Retinopathy
- Stem Cells
- Technological Interventions
- Tolerance
- Wound Healing

JDRF's Research Goals

JDRF plays a unique role in setting the global direction of diabetes research resources, to ensure that they are used as effectively as possible as a "cure enterprise" to bring about a world without diabetes and its complications. To that end, the

organization has identified a set of cure therapeutic goal areas on which it will focus its research funding efforts. JDRF believes some combination of these areas of research focus currently holds the best potential to lead to breakthrough cures and treatments for type 1 diabetes and its complications. JDRF will continue to actively pursue research within the framework of the following goals while remaining flexible enough to quickly respond to new opportunities as they arise:

- Stopping the immune system response that causes type 1 diabetes and restoring autoimmunity in new-onset patients
- Perfecting islet replacement strategies without chronic immunosuppression, including the creation of a renewable islet cell source
- Creating novel therapeutics for predicting, preventing, and reversing complications
- Regenerating the body's own beta cells without transplantation
- Achieving metabolic control through mechanical intervention, including the development of a closed-loop artificial pancreas

FY2006 JDRF Research Funding

Autoimmunity: \$41 million

Complications: \$26 million

Islet Replacement Transplantation: \$21 million

Renewable Cell Source: \$20 million

Regeneration: \$8 million

Metabolic Control: \$6 million

Personal Records

This is a place for families to keep all their personal school related information, forms, letters, etc.