



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

About the Author and the Goal of this Guide 2

I. Communicating with Schools 4

- 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

II. Diabetes Basics 9

- 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

III. Parent/School Partnership 21

- 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 31

IV. Educate the Educator: Staff Training 32

- 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

V. The Rights of your Child with Diabetes 51

- Your child's rights
- Section 504
- Legal rights of the child with diabetes
- References for those who desire more information

VI. Diabetes in the day care setting and in the college years 56

- Diabetes in the day care setting
- Diabetes in the college years

VII. About JDRF 61

- Research funding facts

Personal Records Section 64

TABLE OF CONTENTS

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.

The Juvenile Diabetes Research Foundation (JDRF) offers the information in this manual for general educational purposes only. JDRF reserves the right, in its sole discretion, to correct any errors or omissions in any portion of this manual. JDRF may make any other changes to the manual at any time without notice. This manual, and the information and materials in this manual, are provided "as is" without any representation or warranty, expressed or implied, of any kind. Information in this manual may contain inaccuracies or errors. JDRF believes the information contained in this manual is accurate, but reliance on any such opinion, statement or information shall be at your sole risk. JDRF has no obligation to update this manual, and any information presented may be out of date.

The JDRF staff/volunteers responsible for compiling the resources presented in this manual are not health care professionals. Neither JDRF nor the staff/volunteers engage in rendering any medical professional services by making information available to you in this manual, and you should not use this manual to replace the advice of qualified medical professionals. You should not make any changes in the management of type 1 diabetes without first consulting your child's physician or other qualified medical professional.

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.