The Diabetes Connection

Family Self-Management Newsletter



Fun Knight Event!

Lora Vonderhaar recently surprised her diabetes provider, Dr. Repaske at her last visit when she told him with the help of her school she raised over \$5,000 for Cincinnati Children's Hospital Diabetes Center. Lora and her classmates from Columbia Elementary



School raised the money through an annual fundraiser event the school has being doing since 1999. Approximately 385 fifth and sixth grade students from the school held an evening of fun events including games, prizes, karaoke and inflatables.

Lora and her mom noted that they wanted to give back to the Center and do something to help families who are living with type 1 diabetes. Lora credits her school nurse, Eva Garcher RN, MS, NCSN with the idea of using the event this year to raise money for the Diabetes Center. The money raised from this event will go towards financial assistance for supplies and for toys needed for the floor. Ms. Garcher also works part – time at CCHMC Urgent Care and is the 2008 recipient of the Ohio School Nurse of the Year presented by the Ohio Association of School Nurses.

Lora was diagnosed with type 1 diabetes at the age of four. She noted she will never forget her hospitalization because it was during Christmas. Lora is 12 years old and when not busy with school she enjoys music. She hopes one day to work with animals as a veterinarian.

A huge thank you from the Diabetes Center to Lora, her parents, Eva Garcher and all the fifth and sixth grade students at Columbia Elementary School.



Check presented to Cincinnati Children's Hospital by Jerry Gasper, Columbia Elementary School principal, Lora Vonderhaar, and Eva Garcher, school nurse.

My Challenge

By Lindsey Shipp, 17

Everyday 29,000 children die of hunger, every 30 minutes 600 children die, and if you break that down even more you could come up with the calculation that 3 children die every second due to starvation. Adults are not included in those statistics. People every day die just because they don't have food.

This past weekend I had an experience that will stay with me throughout my life. I went with my youth group from Dry Ridge Christian Church to Lexington to participate in a 30 hour Famine. This was a third annual event which raises awareness of the hunger issue that affects more people than we think. It's something that I will remember clearly not just because it was a challenge to not eat for 30 hours, but to control my diabetes.

I was diagnosed with type 1 juvenile diabetes October 31, 2000. I never thought that I would be able to participate in something like this because of my diabetes. I wasn't sure how my blood sugars would fluctuate and react to not having any food in my system or what the insulin would do without that food. I didn't just want to pass up an amazing weekend I could spend doing such a great thing.

We contacted my nurse practitioner at Children's, and she devised a plan that I could use in order to do this. I set a temporary basal rate for every 3 hours and would check my blood sugar. We were allowed to have juice or water, so I would be able to have juice if I were low or water if I were high. I am grateful that I was able to have done this because I gained a better perspective of what it's like to hungry for a period of time and there are people who do it every day. Having diabetes shouldn't stop us from participating in memorable events like these.

Traveling with Diabetes

By Susan Ketterer, parent representative

Summer is fast approaching, when many families make plans to travel on vacation. While we may take a vacation, our diabetes does not. My daughter, Amanda was diagnosed with diabetes when she was 8. She is now 10, and we have taken many trips with her, including a trip last spring to London and Paris. Here are some tips for traveling with diabetes:

Flying

Check out the Transportation Security Association (TSA) website at tsa.gov. They list guidelines on what you may carry with you on an airplane. Know that you can take all needed supplies, including insulin, syringes, pump supplies, sharps containers, juice to treat a low blood sugar, and gels or frozen liquids needed to keep supplies cool. Supplies should be placed in a clear plastic bag, separate from other non-diabetes supplies. You will need to declare the items to the Transportation Security Officer when you go through security. They cannot require your child to remove his or her insulin pump when going through security; you may request a pat-down and visual inspection if you are uncomfortable with your child walking through the metal detector. You may also request a visual inspection of all your supplies, rather than sending them through the x-ray machine. When we are traveling by airplane, we request a letter from our CNP or doctor listing out the supplies we will have with us.

Supplies

Make out a list ahead of time of all needed supplies. Plan on taking extra supplies. We usually take about twice as many supplies as we think we will need. If you are traveling by car, remember to take along a small cooler or lunch box to keep the supplies cool. If we are staying at a hotel and do not have access to a refrigerator, I take along plastic bags for ice. The Frio products also work well to keep supplies cool. It's also a good idea to take along syringes, even if your child uses an insulin pump. Some pump companies may also provide a back up pump to you when you travel; check with your pump company. It is also a good idea to take along your SOKS procedures (in case your child gets sick and develops ketones) and a record of all pump settings.



Amanda and Sue at the Thames River in London, England

My daughter also wears a Continuous Glucose Monitor (CGM). We did not take extra sensors with us; we have found they are delicate and do not travel well.

Untethered

If you are taking a vacation where your child will spend a lot of time off their insulin pump (beach, rafting, waterpark) you may want to talk to your CNP or doctor about your child going "untethered." When your child is untethered, they use a long-acting insulin to replace all or most of the basal they receive from their insulin pump. My daughter did this for most of last summer and fall. She took a long-acting insulin, and received a small amount of basal from her pump. We did not have to worry about high blood sugars after every trip to the pool, and she did not have to worry about us chasing her around the pool with the insulin pump.

Different insulin needs

You will probably find that your child's insulin needs are different when on vacation. You may need to adjust basal rates and carb ratios due to different activity levels. When we are on a long trip, whether by airplane or car, my daughter tends to drop low at the beginning of the trip and then go high towards the end of the trip. We try to plan for this by adjusting her basal rates. If your child is on shots, you could plan for this by adjusting the carb ratios before or during the trip.

If you plan ahead, traveling with diabetes does not need to be stressful.

Spotlight on the Customer Service Representatives!

For each newsletter we would like to spotlight a different group to help all of our patients and fami-

lies understand who is doing what here at the Diabetes Center. We have chosen to start with the Customer Service Representatives (CSR).

The CSR's are the first people you come in contact with during your clinic and outpatient visits.



Our CSR's are Kim Jones, Nicole Montgomery and



Sonya Porter. Kim, our veteran, has been with the Diabetes Center for 7 years and is an avid belly dancer! Nicole has been with CCHMC for 10 years, 2 as a CSR in diabetes, and is a Cincinnati Reds fan. Sonya is the

newest CSR who joined us a year ago and loves to laugh. They have many responsibilities, with one of them being checking all of the patients in and out. They would like to share with you a few things that will help facilitate a more timely and accurate visit.



- Make sure that you have the most current insurance card. This helps to alleviate billing problems.
- Know your primary care physicians full name and address. This helps to ensure that your medical information is sent to the correct physician in a timely manner.
- ♦ Be prepared to pay your co-pay at your visit.
- Sometimes it can take a while to find a parking place when you come for visits. Arriving 15 minutes early keeps you from being delayed, and helps to keep clinic running on time.
- All questions the CSR's ask you are mandatory for keeping accurate information. Please listen to each question and answer as they are asked.

Next time you come to the Diabetes Center, we want you to have a positive visit, starting with your interaction with the Customer Service Representatives!

Diabetes Technology News

By Marcia Wonderly, RN, BSN, CDE Diabetes RN Educator

Navigator Continuous Glucose Monitoring System Receives FDA Approval

March 13, 2008

The Food and Drug Administration approved the FreeStyle Navigator Continuous Glucose Monitoring System in the United States for people with diabetes who are 18 years of age and older. It will be available in the second quarter of 2008 by prescription only. The sensor is worn for five days and then replaced. A wireless transmitter beams sensor glucose information the receiver. Additional information about the FreeStyle Navigator system is available at www/continuousmonitor.com.

Insulet Corporation and DexCom Announce Development Agreement

January 7, 2008

Insulet Corporation, manufacturer of the Omni-Pod Insulin Management System, and DexCom, Inc. announced they have signed a development agreement to integrate the DexCom™ continuous glucose monitoring technology into the wireless, handheld OmniPod Personal Diabetes Manager (PDM). The anticipated product launch is mid-2009.

DexCom Announces Joint Development Agreement with Animas Corporation

January 10, 2008

DexCom, Inc. manufacturer of the DexCom™ continuous glucose monitoring system has announced that it has entered into a joint development with Animas Corporation to integrate the continuous glucose monitoring technology into Animas insulin pumps. The new technology will enable the Animas pump to receive sensor glucose readings and display this information on the pump's color screen. DexCom™ anticipates the integrated system will be available to patients in 2009 or early 2010.

DexCom[™] Announces "Open Choice" Enhancements

DexCom, Inc. has announced the latest enhancements to their current continuous glucose monitoring system. "The Open Choice" (manual entry) system allows the system to be calibrated using any blood glucose meter and without the use of a calibration cable. It is designed to be used in conjunction with their seven day sensor.

Recruiting Parent Representatives



By Robin Kelly, Parent Representative

I have been part of the Pursuing Perfection Self-Management group as a parent advisor for several years now. Why have I committed to this for so long you ask? For it is certainly a committed choice, I, LIKE ALL PARENTS WANT THE BEST POSSIBLE CARE FOR MY CHILD. I also want to be able to take care of my child on my own.

By attending meetings, I can be a voice for this. We all say at times that unless you truly live diabetes everyday something can get left out of the thought process sometimes. So, as these fine professionals from Children's work so diligently day in and day out to take care of the whole child, physically, emotionally, socially, academically and even their families they always are willing to listen to any comments or suggestions I may have to make in regard to one living the life with diabetes in it. We have all benefited from many things

<u>Committee</u> <u>Members</u>

Parent Representatives

Robin Kelly Susan Ketterer Mary Schutzman

Diabetes Staff Allison Deisinger Tammy DiMuzio Sherry Elmore Shannon Haury Ann Malinowski Alesia Mattar Tamika Poole Marcia Wonderly Joanna Wootten

that have come from these group meetings such as the targeted action plan, sick day guidelines, Halloween party, picnic, newsletter, etc.

So if you want to be a voice and have some time to share, being a parent advisor is self rewarding. We're all in this together wanting the same goal.....a cure first and foremost, but in the meantime, the best care which is what we have in CCHMC and ourselves.

If interested in becoming a parent representative to the Self-Management Committee, please contact Shannon Haury or Allison Deisinger at (513) 636-2444 Option 9.

Assisting Families Dealing with the Struggles of Diabetes Management

By Peggy Crawford, Ph.D. Clinical Psychologist

Since October 1, 2007, Psychology services have been offered in the Diabetes Center by Dr. Peggy Crawford, a clinical psychologist and Dr. Laura Williams, a postdoctoral fellow in the Division of Behavioral Medicine and Clinical Psychology at CCHMC. So far, 115 patients have requested referral to one of the diabetes psychologists. Reasons for referral include difficulty following the diabetes treatment plan and keeping blood glucose levels at a healthy level. In addition, many children and teens requested care for anxiety and depression related to their diabetes, to other life stresses, and often both. Children and teens need close supervision by parents or other adults to test blood glucose and take insulin regularly, day in and day out. This added responsibility can be very stressful for families already busy with multiple demands on their time and energy. Families who come for psychology services before the problems become overwhelming can avoid severe distress and see improvement quickly.

If your family is experiencing conflict about diabetes more days than not, if you suspect your child is struggling to keep up with the many tasks needed to take care of his diabetes, or you're concerned that your child is experiencing anxiety, depression, or behavioral problems, please contact your provider and request that a referral be made. Initial appointments can be scheduled within 2 to 3 weeks and are available every day of the week at morning, afternoon, and after school times. The Diabetes Center is committed to providing resources to you and your child to get through the tough times.

Diabetes Summer Camps

The American Diabetes Association (ADA) offers over 50 camping programs in the United States and serves over 10,000 children each summer.

Camp Tokumto is a week-long day camp for children with type 1 or type 2 diabetes. It is held at Lakeside Lodge in Sharon Woods, in Sharon-ville, Ohio. Campers enjoy meeting other children with diabetes and spending time outdoors while participating in fishing, nature, arts and crafts, nutrition and diabetes education and going on field trips. Campers are supervised by nurses, dietitians, and counselors thoroughly trained in diabetes management.

Camp Dates: June 23 - 27, 2008

Camper Ages: 5-9

Camp Fees: \$200 ADA Members, \$225 Non

Members

Deadline: May 30, 2008

Camp Korelitz is a week-long residential camp for children with type 1 or type 2 diabetes. It is held at YMCA Camp Campbell Gard.

Campers enjoy meeting other children with diabetes and spending time outdoors while participating in swimming, canoeing, arts and crafts, ropes courses, climbing walls, horseback riding, archery, and nutrition and diabetes education games and discussions. Campers are supervised 24 hours a day by doctors, nurses, dietitians, and counselors thoroughly trained in diabetes management.

Camp Dates: August 3 - August 10, 2008

Camper Ages: 8-15

Camp Fees: \$450 ADA Members; \$500 Non-

Members.

Deadline: July 11, 2008

Contact for both camps and financial aid information:

Molly Robertshaw 513-759-9330 ext. 6662 or

mrobertshaw@diabetes.org.

The American Diabetes Association, Southwest Ohio and Northern Kentucky area

644 Linn Street, Suite #304 Cincinnati, Ohio 45203



Other area camps include Camp Hendon, Shepherdsville, KY (30 min south of Louisville) from July 20-26 for ages 8-17, and Camp John Warvel, YMCA Camp Crosley in North Webster, IN from June 8-14 for ages 7-15.

Visit the website at www.diabetes.org for more information, available financial aid, and other camp locations and dates.

School Packets are Ready for Pick-up!!

School orders and packets for the 2008 - 2009 school year are here. Please pick up your packet at the clinic registration desk when you are here for a clinic visit this spring or summer.

It is important for you to sign and complete the form "Authorization for Use and/or Disclosure of Protected Health Information to Schools" before you leave clinic. This form allows us to communicate with school nurses and other school personnel about your child when they cannot reach a parent or have questions.

School forms with the exception of the physician orders will be available on our website at www.cincinnatichildrens.org/diabetes-center.



Upcoming Diabetes Programs for School Nurses

The Diabetes Center offers several programs for school nurses every year. These programs focus on caring for the child with diabetes in a school setting. Upcoming school nurse programs include an all day program scheduled for July 10 and a Mini 2-hour program scheduled for September 11, 2008. Registration is required.

Diabetes Annual Assessment Appointments

It is important for your child's needs to be evaluated on an individual basis once a year by a diabetes nurse educator, dietitian, and social worker. Annual Assessments are recommended by the American Diabetes Association (ADA) and are now routine part of our practice here at the Diabetes Center.

Annual assessments will address a variety of topics such as age appropriate guidance and education, diabetes self-management skills, managing diabetes at school, new insulin therapies, and cutting edge technology in diabetes management. In addition, if your diabetes provider is a nurse practitioner, you will be required to meet with a diabetes physician one time per year.

These appointments will also allow you more time to ask questions about topics that are important to you and your child.



Families Living with Diabetes Support Group

This support group was created in 2004 by several parents who had been meeting over coffee to discuss concerns and helpful tips regarding their children's diabetes management. The group has now grown to over 150 families that receive information and monthly e-mails with updates on the current meetings and typically over 30 families that come to the monthly meetings. The goal of the President, Lora Melin, is to provide resources to families who are living with diabetes and to help everyone stay informed on research, technology, and local fundraising events.

Monthly meetings are at the **Wingate Inn** 7500 Tyler's Place Blvd., West Chester, Ohio 45069 (513) 777-1101. Childcare, snacks, and the "swap and donate" bins for old supplies are always provided.

For more information, including the calendar of upcoming activities, go to www.familieslivingwithdiabetes.com or call Lora Melin-President (513) 907-8954

Did You Know???

Cincinnati Children's Liberty Township Campus opens on 08/11/08!

The Diabetes Center will have appointments available at the Liberty Campus Monday— Thursday, in addition to the Main Campus.

You may schedule appointments at the Liberty Campus by contacting the Call Center (513) 636-2444, option 1 and stating your location preference.

Log on to www.cincinnatichildrens.org and click on "Liberty Campus" for a map, directions, and information about the Community Open House August 2nd.