



CHRONIC HEALTH MATTERS

INSIDE THIS ISSUE:

<i>NH Partner's in Health</i>	2
<i>Training Grants Available for Parents & School Personnel</i>	2
<i>Living with Diabetes: A 14-Year-Old's Perspective</i>	3
<i>Diabetes, Heart Disease and Stroke</i>	3
<i>Diabetes: Learn More Online</i>	4
<i>NH Family Resource Connection Publications on Diabetes</i>	4
<i>CCACHC Annual Meeting</i>	4

CCACHC
21 Fruit Street, Suite 22
Concord, NH 03301

Phone: 603-225-6500
E-mail: ccachc@conversent.net
Web site: www.ccachc.org

CCACHC MISSION

The Council for Children and Adolescents with Chronic Health Conditions and their families is established:

To analyze the barriers in obtaining appropriate and effective community and family-based services and support; and

To advocate and collaborate at state and local levels to improve the capacities of communities to respond to the needs of families with children and adolescents with chronic health conditions

DIABETES: A GROWING EPIDEMIC

By Edward S. Horton, M.D.

Diabetes is a disease in which the body is unable to produce or unable to properly use and store glucose (a form of sugar). Glucose backs up in the bloodstream — causing one's blood glucose (sometimes referred to as blood sugar) to rise too high.

There are two major types of diabetes. In type 1 diabetes, the body completely stops producing any insulin, a hormone that enables the body to use glucose found in foods for energy. People with type 1 diabetes must take daily insulin injections to survive. This form of diabetes usually develops in children or young adults, but can occur at any age.

Type 2 diabetes results when the body doesn't produce enough insulin and/or is unable to use insulin properly (insulin

resistance). This form of diabetes usually occurs in people who are over 40, overweight, and have a family history of diabetes, although today it is increasingly occurring in younger people, particularly adolescents

Officials at the Centers for Disease Control and Prevention estimate that one out of three children born in 2000 will develop diabetes—mostly type 2 diabetes—in their lifetime. Those numbers will only increase unless we start doing a better job at prevention.

Children who at risk for type II diabetes are overweight, in the 85th percentile or above for their age and sex, have parents or close blood relatives with type 2 diabetes,

have higher-than-normal blood glucose levels, blood pressure and cholesterol and triglycerides,

and were under 5 pounds or over 10 pounds at birth.

Studies here at Joslin Diabetes Center show that modest weight loss (5-10% of body weight) and regular, moderate exercise, 30 minutes a day, (like walking) can cut the risk of someone developing diabetes by more than half. Although these studies weren't done on children and teens, we suspect the same strategies will work just as well for them.

Edward S. Horton, M.D. is Vice President of the Joslin Diabetes Center and Professor of Medicine at Harvard Medical School and also directs the outpatient Clinical Research Center. He is a Professor of Medicine at Harvard Medical School, where he also received his medical degree.

EXECUTIVE DIRECTOR'S CORNER

In observance of National Diabetes Awareness Month, the November 2005 issue of Chronic Health Connections features several articles about diabetes, including what it's like to have diabetes from the perspective of a 14-year-old student.

According to Diabetes in New Hampshire Issue Brief – June 2004, Type 1 and Type 2 diabetes is one of the most common chronic diseases in school-aged children and adolescents. Parents of students with diabetes have indicated that their children often experience less than full participation in school functions. Some examples of the issues

confronting students with diabetes include: not being allowed to go on field trips, or they must be accompanied by their parent; being prevented from participating in a sport because the coach may misperceive that students with diabetes can't be good athletes; and not being allowed to eat snacks in class or on the bus.

To address the barriers to access to all school functions for students with diabetes and other chronic health conditions, the Council sponsored a conference on October 28, 2005, *Promoting Partnerships-Achieving Positive Outcomes for Students with Chronic Health Conditions*. The

purpose of the Conference was 3-fold: (1) to increase school personnel awareness of the academic and social needs of students with chronic health conditions; (2) to improve access throughout the school day for students with chronic health conditions; and (3) to assist school teams to develop individual plans for students with chronic health conditions.

We wish to thank all of the authors who contributed articles to this edition of Chronic Health Connections. Please note that Dr. Edward S. Horton will be a featured speaker at the Annual Meeting of CCACHC, November 30, 2005.

A Publication of the
Counsel for Children &
Adolescents with Chronic
Health Conditions

CCACHC
21 Fruit Street, Suite 22
Concord, NH 03301

Phone: 603-225-6500
E-mail: ccachc@converfsent.net
Web site: www.ccachc.org

CCACHC Members

Sylvia Pelletier
Chairperson
NH Family Voices
Parent

Laura Mills
Vice-Chairperson
Parent
Governor's Appointment

Sharon Nordgren
Member of NH House

Dawn Marquis
Parent

Susan Fox
Institute on Disability – UAP
University of New Hampshire

Cheryl B. Frey
NH Department of Insurance

Virginia Irwin
Department of Education

Bill Smith
Parent

Lisa Corr-Kelly
American Lung Association of
NH

Pat Favorite, RN
Nute Middle High School

NH Partners in Health Helps Families Meet the Challenges of Diabetes

My child has just been diagnosed with diabetes. Where can I get help with understanding her problems, and with all the changes that this diagnosis will mean for my family? How can I get in touch with other parents who are facing the same things I am?

Questions like these come from parents all over New Hampshire to NH Partners in Health and we have answers!

Across the state Family Support Coordinators and Family Councils in thirteen locations, listen and respond to what families tell us they need to support children and adolescents diagnosed with diabetes. Here are some examples of what they define as important:

- Increased support for diabetes research
- Scholarships for children to attend specialty summer camps
- Local support groups
- Help with transition issues
- Strong connections to schools for health planning and 504 development
- Inclusive recreation and activities
- Resources for medical equip-

ment and diabetic supplies

- Parent-to-parent connections

NH Partners in Health Family Council's have been listening. In Conway, the Council participated in a Diabetes Walkathon and will participate again this year. All sites provide "camperships" for children to attend Camp Carefree as well as other specialty camps. Local sites provide, through a family flexible fund, financial support for diabetic supplies and medical equipment when not covered under insurance plans, or when other resources aren't available.

Family Support Coordinators are also available to attend health planning meetings and assist in the development of 504 accommodation plans, or to provide resources for health education if that is desired. For example, at the Lebanon PIH site at the Upper Valley Support Group, Ellin Mehrbach, at the request of a parent, is monitoring legislative action on medications like glucagon at school, and questioning state school officials on how they make sure children with diabetes are included in field trips.

Many PIH sites have support

groups for parents of children with chronic health conditions; and parents of children with diabetes are often at the table receiving and giving support.

PIH held a transition conference last spring to address the changing needs of adolescents, in response to a statewide survey that told us parents wanted more help with issues of adolescent transition. Several PIH sites team up with NH's Juvenile Diabetes Research Foundation to distribute "Bags of Hope". In Littleton, the coordinator, Jane Brickett, has developed a mentoring program for parents of children newly diagnosed with diabetes. In Portsmouth, a parent enrolled in PIH mentors other parents, especially those just learning to use the insulin pump.

So is there support for you and your family? You can count on it! This statewide system is available to you whenever you need us. Call the Hood Center for Children and Families at Dartmouth Hitchcock Medical Center at 1-800-656-3333 to locate a Partners in Health site in your area or to get more information.

CCACHC offers Training / Conference Grants to parents and to school personnel for the purpose of attending workshops, seminars, conferences and similar training proceedings that offer an increased awareness, understanding, and knowledge about chronic health conditions.

CCACHC has established a Guaranteed Collateral Loan Fund for eligible families of children with chronic health conditions.

For more information about these programs, please call 1-866-975-6400 or 603-225-6400.

Living with Diabetes: One Girl's Story

My name is Sarah Henkle. I am fourteen years old and have had diabetes for about three years now. Diabetes is a disease that really hurts you from the inside out.

Most people really don't know how dangerous this disease is. If you were to go to the park and see five kids playing a game, I bet you would not be able to tell which one has diabetes. But, in a few years you might be able to, because if you don't take care of yourself when you are younger you might grow up and have a lot of problems. For instance, you might go blind or any of your organs may fail. Worst of all, you could die.

There are two Basic Facts about diabetes that everyone should know. First, anyone can get it at any time. That is why it is important to help raise money so scientists can figure out how people get it. In my case I most likely got it because my dad and grandfather have it (genetically).

The second thing is that if you have diabetes you always have to watch what you eat and how much sugar you take in. This is where the blood glucose testing and the shots take place.

Really, each time you eat something you should test and see what your number is. If you are too high, then you would have to take more insulin than if your number is fine. If your number is too low, you take less insulin instead of more.

For me, the range my doctor wants for me is 80-120. But for each person there is a different target. And if you eat something with more carbohydrates, then you need to do more insulin. If you take a smaller amount of carbohydrates, you do less, just like with the blood

glucose. If you take in too many carbohydrates and don't do enough insulin, your number will become higher than what it already is and if you do too much then your number will become too low.

“There are two basic facts about diabetes that everyone should know. First, anyone can get it at any time. The second thing is that if you have diabetes you always have to watch what you eat and how much sugar you take in.”

And having too high or too low a number is very dangerous, so you should always try your best to keep your numbers in control.

Most people who know about diabetes don't know the true facts. For instance, if you are a diabetic you CAN have sweets and things with a lot of sugar. But you should not have too much. That I would say is one of the most annoying things.

The other big annoyance is when someone keeps asking a question about what I need to do, how I do it. But that's a good thing too, because this is how you can spread the knowledge of diabetes to everyone. And it's how you know that people are thinking about you.

Learn More Online

Family Resource Connection

<http://www.nh.gov/nhsl/frc/contact.html>

1-800-298-4321 (603) 271-1188

<http://www.dhhs.nh.gov/DHHS/CDPC/dep.htm>

http://www.childrenwithdiabetes.com/camps/d_07_1nh.htm

<http://www.healthynh2010.org/diabetes.htm>

1st Diagnoses

http://www.jdrf.org/index.cfm?page_id=103432

Personal Stories

http://www.jdrf.org/index.cfm?page_id=103436

Diabetes In School

http://www.jdrf.org/index.cfm?page_id=103439

Technology Improvements

http://www.jdrf.org/index.cfm?page_id=104077

Make the Link! Diabetes, Heart Disease and Stroke

An educational partnership of the American Diabetes Association and the American College of Cardiology

People with diabetes are at increased risk for cardiovascular disease, namely heart attacks and stroke. Through an educational initiative titled *Make the Link! Diabetes, Heart Disease and Stroke*, the American Diabetes Association and the American College of Cardiology are urging people with diabetes to *make the link* between diabetes and heart disease and stroke. By taking charge of their health and managing risk factors, people with diabetes can help reduce their risk for heart disease and stroke.

The *Make the Link!* Initiative emphasizes the need for comprehensive diabetes care that goes beyond lowering of blood glucose and targets other cardiovascular risk factors. Control of blood pressure and cholesterol is crucial to prevent heart disease and stroke. Research has shown that people with diabetes can live longer and healthier lives with relatively small decreases in blood glucose, blood pressure and cholesterol.

The goals of the *Make the Link!* Initiative are to increase public awareness of the link between diabetes and cardiovascular disease, educate healthcare providers on proper diagnosis and treatment, and inform patients on their risk and appropriate therapies. Pursuit of these goals will help decrease the incidence of heart disease and stroke associated with diabetes.

For more information about the American Diabetes Association, please visit our website at www.diabetes.org or call us at 1-888-DIABETES.

SAVE THE DATE

**COUNCIL FOR CHILDREN AND ADOLESCENTS
WITH CHRONIC HEALTH CONDITIONS
ANNUAL MEETING**

NOVEMBER 30, 2005

**Unitarian Universalist Church
274 Pleasant Street
Concord, NH**

**Business Meeting
8:30 AM to 9:45 AM**

**Annual Meeting
10:00 AM to 1:00 PM**

***The Counsel Would Like To Thank The Sponsors Of This
Year's Fall Conference, Promoting Partnerships:
Achieving Positive Outcomes For Students
With Chronic Health Conditions:***

Ride Away Corporation Interim HealthCare

**Selected titles from NH Family Resource
Connection on the topic of Diabetes**

Active play [videorecording] : fighting obesity & diabetes, and keeping children healthy. Pennsylvania State University.

American Diabetes Association complete guide to diabetes. American Diabetes Association.

The dinosaur tamer and other stories for children with diabetes. Mazur, Marica Levine, 1933.

Don't be blind to diabetes [videorecording]. International Association of Lions Clubs, c1988.

The economics of diabetes mellitus : an annotated bibliography. Centers for Disease Control and Prevention (U.S.).

Even little kids get diabetes. Pirner, Connie White. Morton Grove, Ill. : A. Whitman, 1991.

Gestational diabetes [videorecording] : common sense guide for expectant moms. Altschul Group. Evanston, IL : Altschul Group Corp., c1994.

Handbook of pediatric nutrition. Samour, Patricia Queen. Gaithersburg, Md. : Aspen Publishers, 1999.

I'm tougher than diabetes! Carter, Alden R. Morton Grove, Ill. : A. Whitman and Co., 2001.

The Johns Hopkins guide to diabetes: for today and tomorrow. Saudek, Christopher D. Baltimore, Md. : Johns Hopkins University Press, 1997.

**Council for Children and Adolescents
with Chronic Health Conditions
21 South Fruit Street, Suite 22
Concord, NH 03301**