

Chronic Health Matters

Winter 2007

What do working parents need? Provided by www.massgeneral.org/ebs

Inside this issue:

My Gift	2
Training Grants	3
Special Kids Informa-	3
Camp Scholarships	3
Sibshops	4
Loan Program	4
NH Partner in Health	4

The prevalence of childhood chronic health conditions has increased dramatically over the last several decades. Today, it is estimated that one in five families is caring for a child with a special health care need. As these rates have increased, so has the impact on parents who strive to satisfy the demands of their work life while caring for their child.

The relevance of work and family balance as an important business consideration and initiative has also emerged. In particular, over the last decade, these issues have received significant

attention from employers and the business sector. Yet few companies have focused on employees caring for children with special health care needs (also referred to as children with special needs) when developing employee benefits or work-life programs. An estimate provided by one national EAP and work-life vendor illustrates the magnitude of the issue for employers and benefit providers-between 10-15 percent of the calls they receive involve issues regarding various aspects of raising a child with special needs.

The types of benefits and supports important to employees who have special needs include:

Comprehensive and affordable health insurance

Flexible work arrangements and use of leave time

Supportive work environments

Clear and accessible information about company benefits and how to access to them

Information and community resources and services and public benefit programs.

Help from human resources

With great appreciation the members of the Council for Children & Adolescents with Chronic Health Conditions acknowledge past chair; Sylvia Pelletier for her dedication and support in fulfilling the Council's mission. She has made a difference in many lives of New Hampshire families and proves to be an inspiration to many.

Executive Director's Corner Denise A. Brewitt

It is with great pleasure that I welcome aboard the new Executive Council for CCACHC. The Executive Committee is comprised of dedicated parents who strive to improve the lives of children with chronic health conditions as well as supporting their families in that process.

Sarah Aiken has been elected as our new chairperson and

Rob Taylor was selected as the vice chairperson. Laura Mills who has dedicated years to the Council has transitioned from vice chairperson to treasurer and Sally Weiss was elected as secretary.

All the parents who were elected come from diverse backgrounds; with the life experience of parenting a child with a chronic health

condition.

We also start 2007 with three new members to the Council; Sandra Poleatewich from Interim Healthcare, David Ouellette from New Hampshire Council of Developmental Disabilities and Melanie Gabree a parent of twins from Bedford, New Hampshire.

Welcome!

My Gift *An award winning essay by Chelsea Miller*

Cancer. A word that strikes fear, sadness, or sympathy into the eyes of a listener. Its something that you think will never happen to you; only other unfortunate people get it. Well I guess I'm one of those people; although I am hardly unfortunate.

Late fall of 2005, I would get to school, winded and feeling completely exhausted, even though it was not that long of a walk to my car, parked down the street. I assumed I was either really out of shape or catching a cold like all high school students do. Soon, my pale complexion and constant tired composure caught the attention of friends and teachers, and they urged me to go to the doctors to see what was wrong. I ignored them, thinking it was normal because I normally don't get sick. Plus, I had dance classes on Mondays and Wednesdays, work Tuesdays and Thursdays, and then I worked in a horse stable Friday thru Sunday. And school work and college applications on top of that. I could hardly take time off to rest and get better.

On November 9th 2005, I was brought to the doctor's office and everyone's faces were full of concern as they poked and probed and questioned me. I wasn't very coherent and laid on the table while the nurse took blood samples and my doctors discussed my symptoms to themselves. In the results of my blood tests, they noticed that between the red

blood cells and the white, something wasn't quite right. They sent me up to the Dartmouth Hitchcock Center with the prognosis of my symptoms being either a viral infection or leukemia. I remember thinking to myself, what's the chance of ME getting leukemia? Slim or none... On the evening of November 9th, I was diagnosed with Acute Lymphoblastic Leukemia.

My life, and everything in it, was turned around and flipped upside down. How could something like this happen to me? Was there something that I could have done to prevent it? How am I going to finish my senior year? Will I lose my hair? All these questions were answered with caution from the doctors, as every person is an individual, and so is their cancer. It seemed like a curse to me at first, for a wrong doing that I didn't know that I had done. I was in complete shock and didn't know how to react. I was devastated, sad, angry, confused and felt hopeless. I wasn't the only one in shock though; my family and friends all wondered how something like this, something so awful—and so sudden—just “happen.” This is the type of thing that happens to someone else.

I soon learned, though, that my leukemia is not really a curse at all. In fact, it's a gift. A gift that is non refundable, non returnable. Something I must reluctantly take. In this gift though, I found the courage

I never knew existed, an unconditional love of family and friends, always there, never stopping, never faltering. I was given many prayers from far and wide, and the warmth of knowing that I am truly cared about. I have been given the second chance to wake up and notice things that would have normally been overlooked, instead of sleepwalking through life. I have been given every glorious day to enjoy. My gift, was cancer.

The New England Journal of Medicine published an article in 2006 which highlighted the Childhood Cancer Survivor Study. Of those studied, 62.3% had a least one chronic condition; 27.5% had a severe or life-threatening condition. These were individuals who had received treatment between 1970-1986. While treatments have been improved for both effectiveness and hopefulness, for reduced toxicity, since that time frame, the incidence of chronic health conditions in survivors is still significant.

In the US approximately 12,400 children are diagnosed with cancer per year. In 2006, 52 children were diagnosed with cancer in New Hampshire

“In this gift, I found the courage I never knew existed, and unconditional love of family and friends, always there never stopping, never faltering.”

Parent Training Grants

CCACHC offers Parent Training Grants to conferences and workshops to help parents gain a better understanding of how to deal with their child's chronic health care condition.

Kara Villeneuve shared her experience about her trip to the Parent Project Muscular Dystrophy Annual Conference with the Council.

What the PPMD conference does is bring together families and specialists from across the country, all of who are working hard to forward research,

services and education for Duchenne and Becker Muscular Dystrophy.

It is a powerful feeling to be present with over 600 families all facing the same illness and all hoping to foster change to make their children's lives better. PPMD's founder, Pat Furlong, is truly an inspirational person and hearing her speak of her own struggle with DMD and losing her 2 sons to the disease helped give me hope that all is not lost, and that everyone can make a difference.

We learned the ins and outs of DMD, from the disease progression to treatments to ground breaking genetic research. We left with a sense of responsibility to the whole DMD community to help with advocacy and fundraising efforts, and made some new friends as well.

If you would like more information about the Parent Training Grants that are offered, please contact the CCACHC office at 225-6400 or download an application on www.ccachc.org

Camp Scholarships

The Council is offering scholarships for children to attend camp. This camp must have an educational component that deals with a chronic health condition. Some examples of these camps would be; Obesity Camp, Diabetes Camp and Hematology Camp. The maximum amount granted will be \$250 per camper.

Special Kids Information Program

What is SKIP?

SKIP is a program for children with special health care needs who are increased risk for having to call for an ambulance. SKIP is a way to share information with emergency medical providers. You and your child's physician prepare emergency care providers to care for your child in an emergency situation by telling them about your child's special needs BEFORE the emergency occurs. The SKIP program can improve emergency medical services for children and lower the stress of families before, during and after an emergency occurs.

The SKIP Program is free. It was developed by the NH EMS for Children Project at Dartmouth Medical School with funds from the Bureau of Maternal and Child Health.

How Do I Enroll My Child?

Contact your local EMS provider to get the blue and white SKIP sheet. Complete the sheet to the best of your knowledge. Seek the assistance of your child's nurse or physician for information that you cannot provide and for verification of the medical information. When completed send the SKIP sheet to your local EMS service.

What Does EMS Do With the Information?

Your child's SKIP sheet will be sent to the EMS service closest to your home and in some cases, the information will be shared with the second closest service as well. This gives your local emergency providers the chance to review your child's medical information. This also provides them the opportunity to call or visit with you and your child to become more familiar with your

child's needs.

How Long Is My Child's Information Kept on File?

The average time is one year unless you contact the EMS service. It's a good idea to update EMS every year to any changes in your child's condition as well.

Is My Child's Information Confidential?

Information given to EMS providers is confidential and is shared only with those EMS providers that my respond in an emergency.

How Do I Give My Child's Information to E-911?

You must complete a form called the Supplemental Automated Location Information Worksheet and return it to NH Bureau of Emergency Communications (1-800-806-1242)

To enroll your Child in SKIP Contact your local EMS Provider.

You may also download a skip form on the CCACHC website www.ccachc.org

**NH Bureau of EMS
1-888-827-5367**

NH Partners In Health

Partners in Health is sponsoring a 4 session Parent Leadership Training to begin Feb 2nd and 3rd. A number of parents have applied for this Leadership series which will include learning about the legislative process, taking care of yourself, understanding how to use the media, and developing meaningful projects to make a difference. If you're interested in this wonderful opportunity please call the Hood Center for more information: 653-1483

Sibshops

The Council, along with Partners in Health and CHaD is coordinating a "Sibshop" Workshop to be held on May 11th and 12th. This is a great opportunity to learn how to develop a Sibshop in your own community. Save this date and look for additional information in February.

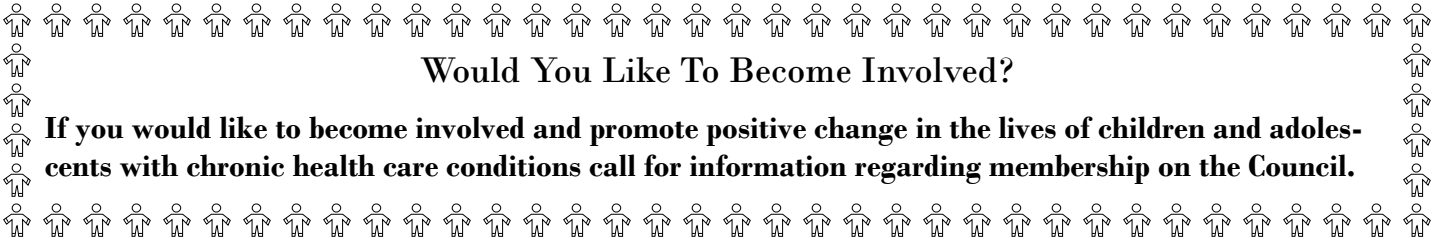


Loan Program

The Council offers a guaranteed collateral loan fund. The program recognizes that families of children with chronic health care needs often face significant expenses for health care, medications, special equipment, and travel as well as decreased income because of time away from work. Please contact the CCACHC office for more information regarding this program.

(603)225-6400

ccachc@conversent.net



Would You Like To Become Involved?

If you would like to become involved and promote positive change in the lives of children and adolescents with chronic health care conditions call for information regarding membership on the Council.

Council for Children & Adolescents with Chronic Health Conditions

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