

**Council for Children & Adolescents
With Chronic Health Conditions**

Annual Report

2008

Submitted by

Bill Smith, Chair

Denise Brewitt, Executive Director

Who We Are... *The Council for Children and Adolescents with Chronic Health Conditions was 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 when responding to the needs of those families with children and adolescents with chronic health conditions.*

What is a chronic health condition?

- *Any biologically-based condition*
- *A condition lasting an extended period of time (three months or longer)*
- *A condition that brings about significant changes in the life of the child and family*
- *A condition that requires more medical care from primary care and specialty providers than typically required by well child and acute illness visits, and which is not primarily defined in RSA-171A, or a mental illness defined in RSA 326-C, or an emotional disability*

Some examples of these conditions are: diabetes, asthma, arthritis, cancer, and PKU.



History and Composition

The Council for Children and Adolescents with Chronic Health Conditions (CCACHC) dates back to 1993 and an executive order from then Governor Stephen Merrill that established an "Advisory Council" on issues impacting the lives of chronically ill children and their families. With the signing of HB 472 by Governor Jeanne Shaheen in July of 1997, the Council was officially established in state statute.

In accordance with RSA 126-I:1, Council membership includes: (a) one Senator; (b) one Representative; (c) one representative from each of the following departments: Health and Human Services, Education, and Insurance, as appointed by their Commissioners; (d) one family member appointed by the Governor; (e) one director of the agency charged by the Council providing services to children and family with chronic health conditions; (f) six representatives of professional and community organizations representing a cross-section of disciplines and constituencies; and (g) up to 13 parents or guardians of children with chronic health conditions.

CCACHC is the only statewide organization that has a legislative mandate to focus on the issues affecting children and adolescents with chronic health conditions.

Council Membership

Denise A. Brewitt Executive Director Parent	Bill Smith Chair Parent
Sarah Aiken Immediate Past Chair Parent	Winn Gianino Vice-Chair Parent
David Ouellette Treasurer Parent	Melanie Kerr-Gabree Secretary Parent
Sylvia Pelletier Family Voices-Related Agency Parent	Senator Maggie Hassan Senate Representative Parent
Representative Barbara Richardson House Representative	Cheryl Frey, MBA NH Department of Insurance Appointed Representative
Lorene Reagan, RN, CDDN Bureau of Developmental Services Appointed Representative	Maria Butler, RN Special Medical Services- Related Agency
Sue Avard, RN Infusion Solutions-Related Agency, Parent	Sandra Poleatewich, RN Interim Healthcare- Related Agency
Sue Avard Infusion Solutions-Related Agency, Parent	Margaret Duffy Arthritis Foundation-Related Agency
Lisa Stockwell Breathe NH-Related Agency, Parent	Barbara Richardson Parent

The Council is fortunate to have a dedicated group of individuals who are working towards a brighter future for all children!

Executive Summary

It is with great pleasure that I present the 2008 Council for Children and Adolescents with Chronic Health Conditions' Annual Report. The Council has made great strides this past year in its efforts to advocate and support our families in New Hampshire.

Across the state, the population of children with chronic health conditions continues to grow. It is now estimated that one in six children contend with a chronic health condition. These children and their families face numerous challenges as a result, including education issues, medical concerns, and family support needs.

With the support of many organizations, the Council continues to work toward eliminating the obstacles that our children and families face. It is my hope that this report will give you an idea of the work the Council did this past year, as well as give a glimpse into any new opportunities in our future. We recognize that little would have been accomplished without the support of collaborative partners, cooperative state agencies, and dedicated individuals. The Council is particularly grateful to all those who worked extremely hard this year in helping the Council accomplish its many goals.

Denise A. Brewitt
Executive Director

Council Goals

- ◁ To promote timely, individualized needs assessments of children and adolescents with chronic health conditions and their families in language easily translated into actions.
- ◁ To provide advocacy and promote family involvement at all levels of health care planning, policy making, advisory, and monitoring capacities.
- ◁ To advocate and collaborate with the New Hampshire Department of Health and Human Services, the New Hampshire Department of Education, and the New Hampshire Insurance Department, as well as other public and private agencies and organizations that serve children and adolescents, in enhancing community-based family supports that meet the unique needs of children and adolescents with chronic health conditions and their families.
- ◁ To increase awareness and visibility in the public and private sector of the medical, educational, social, psychological, and financial issues that impact children and adolescents with chronic health conditions and their families.
- ◁ To facilitate family/physician collaboration at all levels of support and service delivery systems.
- ◁ To empower families with children with chronic health conditions through educational opportunities and the dissemination of information that is understandable, accessible, complete, and presented in a manner that is compassionate and caring.

Council Activities & Accomplishments

Parent and Professional Training Grants

In fiscal year 2008, the Council awarded \$7,500 in training grants to families and school professionals who attended a training, workshop, or conference on a specific chronic health condition. These grants provided individuals with an opportunity to become more informed about treatment and research. The grants also gave them opportunities to spend time with other families having similar life experiences.

Camp Grants

In an effort to help diagnosis specific camps that support children with chronic health conditions, the Council awarded another \$10,000. Regardless of which program the children attend, campers learned important lessons: that they are part of a community and that they are not alone. The programs also allowed children to thrive by creating a safe, comfortable, and fun environment where they could be themselves. And finally, after attending these camps, children and their families felt more confident and capable, as they learned that education is one of the most important tools in managing a chronic health condition.

Guaranteed Collateral Loan Program

In collaboration with Northeast Credit Union, the Council offered a low-interest loan program. This program was established to assist families with the financial burden that a diagnosed chronic health condition can bring. Some examples of what these loans were used for: home modifications, car repair, and medical equipment.

Educational Opportunities for Families

Another important element of the Council's mission this year was to empower those families with children with chronic health conditions. This was accomplished by sponsoring educational opportunities and by disseminating useful information to families. As part of this effort, the Council purchased copies of *Maneuvering the Maze*, a New Hampshire Family Vice publication that was distributed to Partners In Health coordinators and Partners In Health family support council members,

as well as various members of the Council.

Healthy Schools Project

In collaboration with the N.H. Department of Education, the N.H. Department of Environmental Services, the N.H. Asthma Control Program, the N.H. Partnership for High Performance Schools, Breathe New Hampshire, the N.H. Coalition of Occupational Safety & Health, and the Local Government Center, the Council established the Healthy Schools Project to help school districts improve indoor and outdoor environments, and the health of their students and staff.

Through an application process schools were selected for participation in this project. The Council, along with other project partners, worked with each school to form an improvement team, which identified specific environmental issues and asthma management/education needs. Each school then developed an improvement plan for their building. The Council, along with other partners, contributed monies to assist in funding their improvement plans and create a healthier school environment for children.

The Council would like take this time to recognize Lamprey River Elementary School in Raymond, N.H., and Mildred C. Lakeway School in Littleton, N.H., for their dedication to this project. Over the next three years, the Healthy Schools Project intends to work with at least two school districts. It will do this by providing free assessment, training, technical assistance, and mentoring in an effort to address environmental and asthma management needs identified by the schools.

The Council also joined the above Healthy Schools Project partners, along with other groups concerned about air quality in schools, in supporting the passing of HB1171. This bill established a Governor's commission to study air quality in the state's public school buildings. Denise Brewitt, Executive Director of the Council, was appointed by Governor Lynch to this commission.

School Health Committee

The School Health Committee of CCACHC was convened in April of 2006 at the request of Representative Laurie Harding during the 2005-2006 legislative season (in lieu of a legislative study committee).

Representative Harding requested that the Council conduct an in-depth inquiry into those barriers that prohibit access to emergency medications, such as glucagon and diastat. The inquiry focused on children with special health care needs within the school setting. Representative Harding suggested that recommendations be submitted to her and other appropriate parties as to what needs to be changed and who would be in the best position to affect change.

At the request of the Council and the School Health Committee, the Department of Education put forth a rule change to ED 311.02, which was identified as a barrier for school nurses when delegating medications within a school setting. In May of 2008, this rule change was approved and became effective for the start of the 2008-09 school year. This rule change not only allowed school nurses to delegate medications in school, but was also the first time the school day was defined in rule-making.

New Hampshire has a growing population of children with special health care needs. With the rise of this population comes the reality that additional support services are needed within our schools. The Council would like to extend its appreciation to the Department of Education's Katherine Rannie for her participation in this process, along with our dedicated school nurses here in New Hampshire.

Currently, the School Health Committee continues to assist in the transition process of the rule change of ED 311.02. In September of 2008, the Council was contacted by a parent concerned with the first aid training given to school bus drivers and the protocol of action in an emergency situation. The New Hampshire Department of Safety has partnered with the Council to ensure a safe environment for our children while traveling on school buses.

Boards, Councils, & Special Committees on Which the Council is Represented

New Hampshire Interagency Coordinating Council

Denise Brewitt, Executive Director of CCACHC, was appointed by Governor Lynch to the New Hampshire Interagency Coordinating Council (ICC). The ICC is federally mandated under Part C of the Individuals with Disabilities Education Act (IDEA) and serves as an advisory group to the N.H. Department of Health and Human Services, Division of Developmental Services. This agency oversees Family-Centered Early Supports and Services for those children up to age three who have, or at risk of having, developmental delays.

Medical Care Advisory Committee

The Medical Care Advisory Committee (MCAC) was established in accordance to 42 CFR421.12 to advise the state agency's Medicaid Director regarding New Hampshire Medicaid policy and planning. CCACHC's Executive Director was appointed as a member of the MCAC by Governor Lynch and was nominated to the Vice-Chair position in 2008.

New Hampshire Asthma Control Steering Committee

The New Hampshire Asthma Control Steering Committee helps to improve the health status, and quality of life for adults and children with asthma. This committee provides an important network for agencies and organizations committed to creating a healthier lifestyle. Many of the members of the Asthma Control Steering are involved with the Healthy Schools Project and the commission to study air quality in public school buildings.

New Hampshire Alliance for Children

The Council is a member of the New Hampshire Children's Advocacy Network (NH CAN), a project of the New Hampshire Alliance for

Children. Its mission is to drive governmental policy, align budget priorities, and inspire community action to improve the health and well-being of all children and youth. The NH CAN project provides an excellent vehicle for collaborating with other state and local agencies and organizations in an effort to improve life for New Hampshire's children. The Council supported NH CAN in the following legislative priorities:

- Supporting child safety and protection (SB 193)
- Further protection of children from the dangers of lead poisoning (SB 176)
- Expanding the Federal reauthorization of children's healthcare (SCHIP)
- Defining an adequate education (HB 927)
- Opposing the Constitutional amendments to define the state's role in education funding (CACR 18, 19, and 20)

UNH Advisory Board

The need to increase the workforce of Early Childhood Special Education Teachers in New Hampshire was identified and the Council supported the University of New Hampshire (UNH) in seeking out a grant to address this need. CCACHC's Executive Director serves as a member of the Advisory Committee for this awarded grant for UNH. The goal of this program is to improve access to appropriate early childhood education for children with chronic health conditions and disabilities in New Hampshire.

The Partnership to Fight Chronic Disease

The Council is a lead New Hampshire partner in the Partnership to Fight Chronic Disease. The Partnership is a bi-partisan group that worked to assure that chronic health issues were addressed throughout the 2008 presidential race and became an integral part of healthcare reform. CCACHC's Executive Director took part in publicity opportunities on behalf of the Partnership to discuss the relevance and impact of chronic disease on our children. Those opportunities included press conferences with national policy makers and interviews on public radio.

Public Relations

The Council implemented a strategic marketing effort to increase awareness of the medical, educational, social, psychological, and financial issues that impact children and adolescents with chronic health conditions in New Hampshire. The target audience of this effort is parents, caregivers, government leaders, and healthcare professionals.

The public relations program involves several components:

- Print opportunities. CCACHC has been the focus of a variety of articles in New Hampshire publications. Feature stories were published on CCACHC members, various programs CCACHC is involved with, and timely issues related to chronic illness (e.g., medication administration in schools, diagnosis-specific awareness months). Op/ed pieces were submitted to publications covering chronic disease issues. The pieces were submitted on behalf of the Executive Director of CCACHC, as well as State Senators and Representatives. The Council's website includes links to all published stories.
- Radio/television opportunities. The Executive Director, along with Council members, were guest speakers on various radio stations throughout the state, including a bi-weekly show on WKXL called "Your Health Matters." Another highlight was the October appearance of Executive Director Denise Brewitt on Fox News' "Election Headquarters" to talk about the relevance of special health care needs discussion in the presidential election.
- Presentation opportunities. The Council presented at several different venues over the past year, including health education leadership training, school personnel training, and health and local civic groups. The Council also did press conferences with national healthcare policy makers, as well as Dr. Richard Carmona, 17th Surgeon General of the United States, and Dr. Kenneth Thorpe, who served as Deputy Assistant Secretary for Health Policy in the Clinton administration. Also, in August of 2008, Denise Brewitt spoke at the Democratic National Convention in Denver during the Delegates Breakfast. Her speech helped bring national attention to the issues surrounding chronic disease in our children.

Highlight of 2008

Governor John Lynch declared May 25-31, 2008, Chronic Disease Awareness Week in New Hampshire. The Governor asked Granite State citizens to celebrate the week by promoting healthy lifestyles changes, and encouraging people to become better educated on chronic disease prevention, awareness, and management. The Governor – along with Senator Jack Barnes, Senator Maggie Hassan, and Representative Laurie Harding – spoke during a kick-off event at the Historic Walker House in Concord, N.H. Joining the Council and legislators at the Ice Cream Social were members of state and local healthcare organizations, as well as a group of 60 school-aged children, who enjoyed the opportunity to spend time with Governor Lynch.



Celebrating our 2008 Champions for Children

The following individuals were selected as Champions for Children for 2008. These individuals were chosen for their dedication and support to their communities and to children and families. We applaud these individuals for improving access to health care services, empowering families, and improving their communities to support children with chronic health care needs.

Sylvia Pelletier

Sylvia Pelletier, along with several other New Hampshire parents, founded the Childhood Cancer Lifeline of New Hampshire in 1995. The organization's mission is to empower New Hampshire families who are coping with childhood cancer. It accomplishes this by providing knowledge, resources, assistance, and hope. Sylvia wears many "hats," as she has various roles throughout the state. She continues to be a mentor to many thanks to her advocacy for children and families.

Robert Stout R, Ph

A critical resource for any parent who has a child with a chronic health condition is their local pharmacist. Quite often, this individual is the first person a parent contacts after leaving a physician's office. Bob Stout is being recognized for his outstanding service and compassion for families. He has become a mentor to many colleagues thanks to the individualized support and care he gives families. Many have identified Bob Stout as a vital member of their child's healthcare team.

Lynda French

It is with great pleasure that we recognize Lynda French, director of HEAR In New Hampshire. Lynda strives to provide educational, habilitative, and social services for children who are deaf and hard of hearing. French and a dedicated staff of teachers provide support to families by expanding their awareness of resources, and empowering and enabling their children to take their place in the world.