



Council for Children & Adolescents with Chronic Health Conditions

Chronic Health Matters

Governor Declares Chronic Disease Awareness Week

Concord, N.H. - Governor John Lynch officially declared May 25th -31st Chronic Disease Awareness Week in New Hampshire. The Governor asked New Hampshire citizens to celebrate the week by promoting healthy lifestyles changes and encourages people to become educated on chronic disease prevention, awareness, and management.

The proclamation was made at a ceremony held at the Upham Walker House in Concord, N.H. Gov. Lynch, along with New Hampshire Senator Jack Barnes, Senator Maggie Hassan, and Representative Laurie Harding, joined together in asking New Hampshire citizens to help raise aware-

ness for the nearly half a million state residents that contend with a chronic disease.

Governor Lynch was also joined by the Council for Children & Adolescents with Chronic Health Conditions (CCACHC) and the Partnership to Fight Chronic Disease, two organizations that raise awareness for chronic disease issues in New Hampshire. Chronic disease affects the lives of nearly half a million Granite State residents.

Two out of every five citizens live with a chronic disease and one in six children contend with a chronic health condition. These children and their families face numerous challenges,



Six-year-old Ryan Brewitt (right) tossed a pitch to New Hampshire Gov. John Lynch to officially begin chronic disease awareness week.

including education issues, medical concerns, and family support needs as a result of their health conditions.

Governor Lynch and CCACHC urged the citizens of New Hampshire to im-

prove the quality of health care for those with chronic disease and to promote chronic disease prevention

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'Across The Spectrum': How One Council Member Got Involved

The demands of caring for newborn twins can be a daunting task for even the most experienced and prepared parents. Having a newborn twin that has a chronic illness only makes the parents' responsibilities more challenging. Melanie Gabree of Bedford, N.H.,

knows this firsthand.

In March of 2006, Gabree gave birth to fraternal twin boys: Alex and Will. Days after the birth, Alex was diagnosed with phenylketonuria (PKU), a genetic disorder characterized by the inability of the body to metabolize the es-

sential amino acid phenylalanine. Phenylalanine is an essential amino acid found in nearly all foods that contain protein. Bottom line: Alex can have very, very little protein in his diet.

Gabree and her husband,
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Medical Homes Model Improving Pediatric Care Services

According to the American Academy of Pediatrics, there are currently 9.4 million children in the U.S. with special health care needs (or one out of every five households). These children account for 80 percent of pediatric health care expenses.

Ever-rising health care costs, gaps in preventive care, and sub-par management of chronic conditions have forced many state public health agencies to focus on improving pediatric health care services, particularly for those children with, or at risk for, special health care needs. This is where the concept of the patient-centered medical home comes into

play.

Medical homes are not actual, physical dwellings, but a conceptual model for pediatric care that aims to simplify a process involving a complex set of health care needs. Built upon a coordinated and comprehensive partnership between health professionals and families, the goal of medical homes is to provide comprehensive primary care services, medical case management, and other support for children with special health care needs.

Ideally, a medical homes approach gives parents a foundation upon which effective and efficient family-centered care can be planned and pro-

vided. It gives parents a "voice," as well as a better sense of their child's current care status and what future care will entail. The idea is to deviate away from fragmented care, and have the family, the primary care physician, and other service providers work to implement a specific care plan as an organized team.

The Council is an advocate for the medical home model and believes that with the collaboration of families, insurers, government, medical educators, and other components of the health care system, the quality of life for children with special medical concerns can be improved.

Governor Lynch Declares Chronic Disease Awareness Week in N.H.

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awareness by making healthy lifestyle changes in their own communities, places of employment, schools, and homes.

"Children with chronic illnesses and their families face numerous challenges," said Denise Brewitt, CCACHC's executive director. "Our goal is to educate parents and caregivers on these challenges and the many healthcare options they have. Education may lead to prevention. Governor Lynch's proclamation will go a long way towards helping us achieve that goal."

"We applaud Gov. Lynch and the

state of New Hampshire for recognizing the growing problem of chronic disease. By uniting in our commitment to shine a spotlight on this crisis that impacts every New Hampshire resident - and every American - we can save precious lives and needlessly spent dollars," said Dr. Ken Thorpe, executive director of the Partnership to Fight Chronic Disease.

Also on hand for the proclamation was Ryan Brewitt, who is challenged with a rare chronic disease. Ryan first met Gov. Lynch last year when the Governor honored him at a State-house ceremony after being nominated as the state's Champion Child,

"We applaud Gov. Lynch and the state of New Hampshire for recognizing the growing problem of chronic disease."

Dr. Ken Thorpe, Partnership to Fight Chronic Disease

an honor given to children across the country who face severe medical challenges. At that meeting last May, Governor Lynch gave Ryan the first-pitch baseball he threw at a Red Sox game.

New Hampshire 'Champion for Children' Recipients

The Council for Children and Adolescents with Chronic Health Conditions named three New Hampshire "Champions for Children" at its annual meeting Nov. 19. The recipients were: Sylvia Pelletier of the Childhood Cancer Lifeline of New Hamp-

shire, pharmacist Robert Stout of the Hannaford pharmacy in Raymond, N.H., and Lynda French of HEAR IN New Hampshire. These individuals were recognized for their service and support for children with chronic health conditions.



**CHECK OUT THE NEW
COUNCIL WEBSITE!**

CCACHC.ORG

Honoring National Childhood Cancer Awareness Day

Concord, N.H. - On Sept. 13, the Childhood Cancer Lifeline of New Hampshire and the Council for Children and Adolescents with Chronic Health Conditions (CCACHC) observed National Childhood Cancer Awareness Day with a ceremony in Concord, N.H. Sept. 13 is recognized as National Childhood Cancer Awareness Day thanks to a Senate resolution introduced by U.S. Senators Wayne Allard (R-Colo.) and Hillary Rodham Clinton (D-NY). Childhood cancer is the number one disease killer and the second overall leading cause of death of children in the United States. More than 10,000 children under the age of 15 in the United States are diagnosed with cancer annually. Here in New Hampshire, approximately 50 children each year are diagnosed with cancer.

"We feel that National Childhood Cancer Awareness Day serves two purposes," said Sylvia Pelletier, president of the Childhood Cancer Lifeline of New Hampshire. "Pediatric cancer can be a deeply personal tragedy, and this day gives parents, caregivers, and children the opportunity to come together, and give care and support

to one another.

"At the same time, National Childhood Cancer Awareness Day educates those individuals who don't understand the full implications of this disease. Pediatric cancer comprises only one percent of all such diagnoses, so it typically does not garner as much attention as cancers affecting adults. However, the financial, emotional, and physical toll upon children contending with cancer, as well as their families, is no less daunting."

The event took place at the Barley House in Concord. Members of CCACHC and the Childhood Cancer Lifeline of New Hampshire were in attendance, as well as Granite State families who have benefited from the Lifeline's many services and staff members from the Lifeline's popular family camping event, Camp Winning Spirit, held each Labor Day weekend at YMCA Camp Coniston in Croydon, N.H.

Denise Brewitt, CCACHC's executive director, read a proclamation signed by Gov. John Lynch that declared Sept. 13 as Childhood Cancer Awareness Day in New Hampshire.

"Pediatric cancer can be a deeply personal tragedy, and this day gives parents, caregivers, and the children the opportunity to come together, and give care and support to one another."

Sylvia Pelletier, Childhood Cancer Lifeline of New Hampshire

She also presented Pelletier with the 2008 Champions for Children Award.

Also speaking was Sandra Konrad of Manchester, N.H., who shared her family's experiences with pediatric cancer. Her son Ethan was diagnosed with a rare cancer. Konrad talked about Ethan's journey and how the family recently celebrated his five-year anniversary out of treatment.

"As parents, we remember what it's like to journey through each day," Pelletier said. "We manage home care for our children with cancer, all the while trying to attend to the needs of our healthy children as well. The Lifeline understands how trying these days can be, so families are urged to call any time with questions or just for support."

'Addressing Children Across The Spectrum': How One Council Member Got Involved

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Mike, saw their world turned upside-down. "We had the boys in the NICU, where they were taking care of the typical preemie issues," Gabree remembered. "But once Alex was diagnosed, we had to bring him to Boston and keep Will at the NICU. It was all sorts of chaos. Leaving behind one of the boys like that was very difficult."

Once the twins were home, Gabree and her husband began closely monitoring Alex's protein intake. A low-protein diet prevents the buildup of phenylalanine in the blood stream.

Excessive levels of phenylalanine can cause damage to the brain and other neurological deficits. Alex's diet consists of carefully measured amounts of fruits and vegetables, special low protein foods, and a phenylalanine-free medical formula, so he gets the necessary protein.

The need for further information and support is what ultimately led Gabree to the Council for Children and Adolescents with Chronic Health Conditions. She joined the Council in an effort to engage and educate herself on local support resources for children. Today, she is the or-

ganization's secretary and was recently named by New Hampshire Governor John Lynch as his appointed member of the Council.

The Bedford resident takes pleasure in knowing she is helping children with chronic illnesses and their families - much like she was supported during the early days of Alex's condition.

"I really like the fact that the Council doesn't cover one particular disorder," Gabree said. "It addresses children across the spectrum. The Council members put so much energy into helping others."

The Council for Children and Adolescents with Chronic Health Care Conditions was established to advocate and collaborate with state and local agencies to assess and improve: access to regular school and health care; the capacities of communities to respond to the needs of children with chronic health conditions; and the delivery of meaningful services and support.

Denise Brewitt, Executive Director Bill Smith, Chair
Sarah Aiken, Previous chair Melanie Gabree, Secretary
Winn Gianino, Vice Chair
David Ouellette, Treasurer

Contact information: CCACHC, 21 South Fruit Street, Walker Building, Suite 22, Concord, NH 03301

Email: dbrewitt@ccachc.org Phone: 603-271-7045

Across the country, more and more states are developing programs to combat poor indoor air quality in public schools. New Hampshire is no exception. Recently, Gov. John Lynch signed a bill that created a commission to study air quality in New Hampshire's public schools. CCACHC supports Healthy Schools, Healthy Children, Healthy Minds Project.

For more information about this exciting project please visit the [ccachc](http://ccachc.org) website!

WWW.CCACHC.ORG

What Is A Chronic Health Condition?

Chronic health conditions cover a wide variety of diagnoses, ranging from asthma and allergies to diabetes, hemophilia, neuromotor disorders (such as spina bifida, muscular dystrophy, etc.), and cancer.

The Council for Children and Adolescents with Chronic Health Conditions (CCACHC) has defined a chronic health condition to include the four contributing factors:

- Biologically-based
- Lasting for an extended period of time
- Bringing about significant change in the life of the child
- Requiring more than the usual amount of medical care.

How does a chronic health condition affect a child?

By definition, chronic diseases are treatable, but not curable. Children with chronic illnesses visit their doctors more frequently and may endure more hospital visits than healthy children. A chronic condition is long lasting and a child's wellness may fluctuate. The course of a chronic health condition is unpredictable. Children with chronic illnesses may be healthy or ill at any given time.

How does a chronic health condition affect a family?

A child's on-going health condition can cause an enormous amount of stress on the entire family, both emotionally and financially. These children and their families face numerous challenges, including school and education issues, insurance and medical concerns, and family support needs. For more information on chronic health conditions, visit CCACHC's web site at www.ccachc.org.