



**COUNCIL FOR YOUTHS  
WITH CHRONIC CONDITIONS**  
Facilitating inspirational change.  
PO Box 396, Concord, NH 03302  
603.319.4789 • [www.nhcycc.org](http://www.nhcycc.org)



The Council for Youth with Chronic Conditions (CYCC) defines a chronic condition by four contributing factors:

- lasting for an extended period of time
- bringing about significant change in the life of the child
- biologically-based; and
- requiring more than usual medical care.

#### **Mission:**

The Council for Youth with Chronic Conditions was established to advocate and collaborate with state and local agencies to assess and improve the capacities of communities to effectively respond to needs of youth with chronic health conditions and to provide meaningful support to them and their families.

#### **Guiding Principles:**

The Council's guiding principles ensure that our youth with chronic health conditions have:

- Affordable Access to Care
- Supportive Home and Community Environments

And that their families have:

- Family-supportive work environments

## **Council for Youths with Chronic Conditions**

# **2017 Annual Report**

**"Facilitating Inspirational Change"**



When a serious health condition strikes a child, it can hit a family like a tidal wave – washing away all stability and replacing it with endless work and worry. Surprisingly, many families with youth who experience chronic conditions come through stronger; demonstrating incredible resilience and a grateful appreciation for health and the simple gift of life.

In order for children and youth who experience chronic conditions (YCC) to thrive and develop resilience, however, they must obtain appropriate and effective community- and family-based services and supports. Among NH children and adolescents, it is estimated that at least one in six contend with a chronic health condition. These youth face numerous complex challenges, ranging from physical impairments to activity and education restrictions to life disruption to isolation.

Recent scientific research indicates another complication and challenge facing many of our youth: adverse childhood experiences (ACEs). ACEs like poverty, maltreatment, neglect, and other traumatic experiences are linked to the increased likelihood of negative health outcomes, including chronic conditions.<sup>1</sup> Unfortunately in NH, twenty-three percent of our children have experienced two or more ACEs, putting them at higher risk for developing chronic conditions and complications as a result.

When a serious health condition strikes a child, it can hit a family like a tidal wave – washing away all stability and replacing it with endless work and worry. Surprisingly, many families with youth who experience chronic conditions come through stronger; demonstrating incredible resilience and a grateful appreciation for health and the simple gift of life.

This past year, we recognized the limits of our reach as a small council and began to concentrate on strengthening our partnerships. We focused on three constituency groups: disease/condition advocacy groups; public/government organizations that serve children with chronic conditions; and child/youth-focused policy advocate groups. Collaborating with our partners, we are identifying key policy challenges and working together to make changes to meet the needs of our YCC and their families.

The council also focused on improving our communication and social media presence with a revised web site and expanded Twitter and Facebook activity. We continue to stream line our operations to be more efficient, focused and productive. We have increased our ranks to include new council members. Together, council members created new targeted initiatives building on our signature Champion Children annual awards luncheon.

I'd like to thank the members of CYCC for their dedicated service. Although we can't make the diseases or conditions go away, we can improve life for sick kids and struggling families. We are small but when we focus our efforts, we can make a big difference in a child's life.

Sincerely,  
Jeff Woodburn  
*Executive Director*

<sup>1</sup> Prioritizing Possibilities for Child and Family Health, Sept-Oct 2017, Academic Pediatrics, Vol 17, Issue 7, [http://www.academicpedsjnl.net/article/S1876-2859\(17\)30354-6/fulltext](http://www.academicpedsjnl.net/article/S1876-2859(17)30354-6/fulltext)



Council for Youths with Chronic Conditions

Joelle Martin	Milford, Chair
Sarah Aiken	Concord, Vice Chair
Michael Rollo	Rollinsford, Treasurer
Laurie Fleming	Derry, Secretary
Paula Garvey	Amherst
Loretta McGrail	Rochester
Lisa DeMartino	Gilford
Audrey Gerkin	Brentwood
Deodonne Bhattarai	Concord
Sen. Donna Soucy	Manchester
Mariellen J. MacKay	Nashua
Chris Santaniello	Concord
James Fox	Concord
Nancy Wells	Concord

Who We Are:

The Council for Youths with Chronic 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 to respond to the needs of families with children and adolescents with chronic health conditions.

Who are the children with chronic health conditions?

- Biologically-based condition
- Lasting an extended period of time (3 months or longer)
- Bringing about significant changes in the life of the child and family, and
- Requiring more than the usual amount of medical care from primary care and specialty providers than typically required by well child and acute illness visits, and which is not primarily as defined in RSA- 171A or a mental illness as defined in RSA 326-C or other emotional disability.



Values

- Strengthen and recognize families and youth as integral decision- makers. We are family driven.
- Support systems change that anticipates and is responsive to accommodation of all citizens.
- Lead with and focus on strengths, inspiration, and resilience.
- Promote and support improved healthcare options, access to care and services.







## Champion Children (cont.)



### Eliot Perry

Nominated by Jennifer McGhee and Jenna Raizes

He has never let his small stature or disabilities intimidate him from doing things that even healthy adults may think twice about, including speaking with astuteness and confidence to large groups about the struggles he's faced and how individuals can help those that have helped him. Elliot's raced Fungo around the bases without hesitation, even though his leg braces weren't comfortable. He's served as an ambassador for Easter Seals, stood beside Manchester Police and State Police officers who were raising funds for CHaD, led fundraising walks, met with Senators and Congressmen, traveled on behalf of advocacy, and maybe most importantly- shown his peers (including my now three year old) and his parents' peers (like me) that caring for and being kind to others is the most positive way to live.

### Tucker Sharpe

Nominated by Rich Pezzillo

Tucker, a nine-year-old boy from Concord, has severe Hemophilia- a rare bleeding disorder when the body is missing sufficient protein to form a clot. Tucker has raised over \$20,000 for the New England Hemophilia Association's Annual walk, is a participant at NEHA's Annual Family Camp, has advocated at the State House for issues important to those with a bleeding disorder, and represented New England during a national swimming competition for those with a bleeding disorder in Phoenix, AZ. Tucker is a true young advocate for our community and role model to many.



### Hailey Walles

Nominated by Laurie Fleming

Hailey is an amazing young lady who has persevered greatly despite having a complex medical history. She was a premature baby who suffered from critical health needs and seizures. Despite her extensive medical needs, Hailey comes to school every day with a smile on her face and eager to learn. Hailey is a pleasure to work with and her teachers and peers just adore her. She has an amazing personality and is extremely social. Hailey is also a great self-advocate for her personal needs. Hailey continues to amaze and inspire those around her.

## History and Composition



Former State Rep. Barbara French, a long-time school nurse and child advocate was the Honorary Chair of the annual Champion Children awards luncheon. She told a vivid story of how she worked with her school to make accommodations for a wheelchair-bound student. This was a good reminder of how far we have come to ensure inclusive education for all children.

The Council for Youths with Chronic Conditions (CYCC) dates back to 1993 when it was known as the Council for Children and Adolescents with Chronic Health Conditions (CCACHC). Then Governor Stephen Merrill established this advisory Council by Executive Order to focus on issues that impact the lives of chronically ill children and their families. With the signing of HB 472 by Governor Jeanne Shaheen in July 1997, the Council was officially established in state statute.

In accordance with RSA 126-1:1, 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, 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.

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

“ A nation is only as healthy as its children. ”

-Harry Truman

## 2017 Meeting Schedule for the Council for Youths with Chronic Conditions

January, 10th  
Tuesday - 6 pm  
Upham Walker House, Concord  
Regular Meeting

April 13th  
Wednesday - 7:00 am  
Meeting and Tour

May 16th  
Wednesday - 6 pm  
Annual (Budget, Elections) Meeting

September 12th  
Wednesday - 6 pm  
Upham Walker House, Concord  
Regular Meeting

November 14th  
Wednesday - 7:17 am  
Holiday Inn, Concord  
"Champion Children" awards ceremony (lunch included)

*We continued our involvement in the growing effort to combat childhood poverty, which has become popularized by Robert Putnam's book "Closing of the Opportunity Gap for Our Kids" and film "Rising of America," as well as other Adverse Childhood Experiences. The evidence is clear: traumatic childhood experiences can trigger chronic mental and physical health problems. Early investment and prevention is the best and most effective approach. Out collaboration extended to partners working to improve early childhood investment, Early Support Systems, improved \_ screening, access to behavioral health, dental care, respite and inclusive, robust public education systems to name a few.*

## Guiding Principle #1 - Collaborate to Ensure Quality, Affordable Health Care

Since one-third of all children with special health care needs rely on Medicaid or the Children's Health Insurance Program (CHIP) for their health care needs, state policies that govern private and public insurance are vitally important to our youth with chronic conditions. The CYCC has long focused on providing insights and information about the benefits of expanding, high quality, community-based health care as well as the state's Medicaid Expansion Program, or NH Health Care Protection Plan. We've convened meetings with partner advocates to listen to and assist them. We've found that our voice is larger when we join together.

### CYCC Policy Luncheon

This fall, we hosted our first-ever public policy luncheon for state leaders and stakeholders to discuss the value of increased access to quality care. The program explored the results of a recent study that compared life spans of Cystic Fibrosis (CF) patients in Canada and the United States. The results were concerning as Canadians with CF live on average 10 years longer than their U.S. counterparts. Presentations were made by Dr. Brian O'Sullivan, Professor of Pediatrics at the Geisel School of Medicine at Dartmouth College and Lynn Feenan RN, MS, coordinator of the New Hampshire Cystic Fibrosis Center at Dartmouth Hitchcock. Key state leaders and stakeholders in attendance learned a great deal and generated a good discussion. The basic take-away of the research included the importance of consistent access to care; embedding prevention in daily life and catching smaller, relatively inexpensive problems early.

## Celebrate the Resiliency of YCC and Their Families

The CYCC seeks to amplify the voice of families of youth with chronic health conditions. By creating public opportunities to raise awareness of the concerns as well as accomplishments of this population we encourage not only sound policies but also better understanding, greater acceptance and more inclusion. Our signature initiative again this year was our annual Childhood Chronic Condition Awareness Week and Champion Children Award Luncheon. Barbara French served as the honorary chairwoman of the week. A nonagenarian, French is a well-known fierce and effective advocate for children as a long-time school nurse, State Representative and nurse at the NH State Hospital, Department of Education and Health and Human Services Department.

Eighteen youth were presented with Champion Children Awards for their resiliency and courage dealing with chronic conditions. Two long-time CYCC leaders – Bob Quinn, a former Council Chair, and Michael Dennehy, a former Council secretary -- were honored for their service as Champion for Children Advocates. Peggy Small-Porter of the Richie McFarland Children's Center, and Borja Alvarez de Toledo and Keith Kuenning of Child and Family Services NH, were presented with Champion for Children Advocate awards for leading the successful advocacy efforts to increase state funding for Early Supports and Services. Our event sponsor, Eversource, was the recipient of the Business Leadership Award for their contributions to our on-going efforts.

## Champion Children (cont.)



### Sadie Mccallum

Nominated by Deodonne Bhattarai

**Sadie is 11 years old and loves learning, reading, writing stories, inventing, doing advocacy work, and playing with her siblings and her dog. Over the last three years, Sadie has focused her curiosity and creativity on inventing unique mobility solutions for herself and others who are, like her, also physically disabled. In the last year, Sadie has also gotten involved in healthcare advocacy both on the local and national level, and is excited about further opportunities to do advocacy work both for healthcare and for the disabled community!**

### Wyatt Paddock

Nominated by Lisa Maclean

**Wyatt has a significant chronic condition, and yet he comes to school always doing and giving his best, both in attitude and academics. When he was granted his Make-A-Wish opportunity last year, he chose to use it to collect backpacks of items for the homeless. He's a delight to be with and has already begun interfacing with the world with a focus on what he can do for others.**



### Ryan Page

Nominated by Astrid Wielens and Zebra Crossings

**When Ryan was born, he had the longest gap doctors had ever seen in a baby with esophageal atresia, a gap between the top and bottom parts of his esophagus. Doctors initially inserted a G-tube to feed him because he couldn't eat on his own. He had surgery that was unique at the time and Ryan didn't come home until six months old and he needed to learn how to eat. Now at age 13, he is still affected by his condition as he takes medications when he feels sick. Ryan now loves being able to go to Boston Children's Hospital to meet other parents and to give them hope that their child will eat at some point. He is an extremely thoughtful kid and always works to make others feel included. He is truly an amazing kid.**



The Champion for Children organization Advocate Award-Winners were the Richie McFarland Center and Children and Family Services for their advocacy for early childhood supports. Peggy Small-Porter, of the Richie McFarland Center, receives the award from Joelle Martin and Jeff Woodburn.





The Council for Youths with Chronic Conditions supports the 45th Annual NH Snowmobile Association and Easter Seals' Ride-In benefiting Camp Sno-Mo, a residential camp for children with disabilities and special health care needs, was held in Gorham recently. Among those participating were, from the left, Elliot Perry, Easter Seals Child Representative, Major John B. Wimsatt, Law Enforcement Division, New Hampshire Fish and Game Department, Larry Gammon, President and CEO, Easter Seals NH, Maine and Vermont/Farnum Center, Sen. Jeff Woodburn, Executive Director of the Council for Youths with Chronic Conditions, Monica Pettengill Jerkins, Executive Director, New Hampshire Snowmobile Association, Robert Kelly, Regional Director of Camping/Camp Sno-Mo, Easter Seals, Beth Palmer, President, New Hampshire Snowmobile Association Mike Cormier, Vice President of Development, Easter Seals NH and Vermont.

## Champion Children (cont.)



### Elisabeth Hunter

**Nominated by Rev. Kate Atkinson**

**Elisabeth sings beautifully, plays soccer, loves drama, art, baking, crocheting, is a volunteer at the McAuliffe-Shepard Planetarium, has worked with dementia patients, is a Make-A-Wish ambassador, and was a 2017 member of the Capital Area Student Leadership program. At Bow High School, Elisabeth is a member of the chess club, and has received high honors in both her Freshmen and Sophomore years. Elisabeth has Muscular Dystrophy-and a smile that, like Elisabeth herself, does not quit!**

### Mitchell Juneau

**Nominated by Meg Jenkins**

**This young man has made huge progress in overcoming a life changing Traumatic Brain Injury as a Freshman. He has progressed from tutoring at home, to continuing with college prep level classes, with academic rigor and integrity. Mitch has developed self-advocacy skills at an early age that will carry him as far as he continues to prepare for college and adult life.**



### Caia Kimball

**Nominated by Alana Kimball**

**Caia is an active third grader with asthma, allergies, and suffers from lung infections. She understands that the show must go on and performs in her dance competitions and recitals as well as her violin and choral performances even when she is not feeling well. Caia has shown care for other children that have shared her hospitalization experiences through Girl Scout cookie and personal toy donation drives.**

### Kaley Lambert

**Nominated by Maria Lucia Petagna, Family Support Coordinator**

**Kaley is a remarkable young lady who was diagnosed with Type 1 diabetes when she was only 14 months. Despite her diagnosis and the challenges that come with it, she embraces life with grace, resiliency, and optimism. She excels academically and artistically, is engaged in the community, and is a wonderful friend, daughter, and an inspiration to everyone around her!**



## Guiding Principle #2 - Foster Supportive Home- and Community Environments

Each year, CYCC members conduct an educational tour that expands our network and knowledge about home- and community-based services available to families with children who experience chronic conditions. This year we toured Cedarcrest Center for Children with Disabilities in Keene.

Another goal of the council is to support and showcase local initiatives that provide unique services, programs and activities to YCC and their families. This year we spotlighted Camp Snow Mo and Zebra Crossings, summer camps that serve children with special health care needs. CYCC Executive Director Jeff Woodburn toured the two camps, Camp Snow Mo, in Gilmanton Ironworks and Kingston-based Camp Lincoln (one of Zebra Crossings' camps), and visited with the campers.

Each year, the council also recognizes a small, local non-profit that's making a difference in the lives of NH youth who experience chronic conditions. This year we presented the "Spirit Award" to Maureen Tracy of Merrimack, who launched a New Hampshire Chapter to support youth who experience Prader-Willi Syndrome. (Prader-Willi Syndrome is a complex genetic condition that causes a constant sense of hunger and can lead to a number of physical, mental and behavioral problems.)

## Guiding Principle #3 - Foster Family Supportive Work Environments

Balancing work and family is often listed as the most pressing problem for parents of young children. If a child in the family experiences a chronic condition it becomes exponentially more difficult and for many, nearly impossible. Even though benefits exist for in-home care and support, NH parents continue to find it extremely difficult to find consistent, reliable care due to tight workforce challenges and entry restrictions for some professions. Add to that the financial demands of working less or not at all, and these demands can create havoc in the home.

As previously mentioned, the CYCC is dedicated to fostering family-supportive work environments. This past year we collaborated with several partners to advocate for legislation to create a Family and Medical Leave program in our state.



CYCC Jeff Woodburn, left, and Michael Rollo, right, along with Fungo, the Fisher Cat's mascot, presents William Crag, of Eversource, with the Champion Children Business Award at the annual Champion Children event.





Tim Guidish, of Merrimack, Cystic Fybrosis' State Advocacy Chair, makes a point at public policy lunch in September.

## Champion Children

The Council for Youths with Chronic Conditions' signature event is the "Champion Children" award luncheon, which is the kick-off of the annual Children with Chronic Health Care Conditions Awareness week. Children are nominated by school nurses, teachers, health and community leaders for this recognition. We are proud to highlight the



### Olivia Bennett

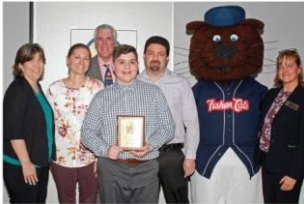
Nominated by Lisa Maclean

Olivia has multiple diagnoses and has had some specific health struggles this year as she made the transition to high school. Despite that challenge, she has embraced her entry to high school with smiles for everyone and never a single complaint about her health. She is a ray of sunshine for her teachers, paras, and a peer, reminding us all what it is to be brave and kind.

### Tyler Carson

Nominated by Sylvia Pelletier

Tyler experienced mobility limitations for years subsequent to his treatment for cancer. All of that time, he was an active participant at family events hosted by the Childhood Cancer Lifeline, whether in a wheelchair pushed by his dad or riding a hand-cycle. This year, ambulatory at family camp for the first time, Tyler spent his time actively supporting a new camper, who was in a wheelchair, demonstrating a true spirit of friendship.



### Abaigeal and Madelyn Conway

Nominated by Denise Raymond, School Nurse

They are twin sisters and high school juniors dealing with the daily challenges of being a teenager with Type 1 insulin dependent diabetes, they focus on rigorous coursework by taking on honors challenges. They have strong academic ability and leadership in the classroom. Abby and Maddy are self-directed, kind, caring, and motivated. Abby was diagnosed with Type 1 insulin dependent diabetes at the tender age of 4. Her twin, Maddy, ten years later, was also diagnosed with Type 1 insulin dependent diabetes at the age of 14 years. They are Junior Squad Leaders with Riding on IIJsulin. This is a program that empowers kids with Type 1 to live healthy, active lifestyles all while managing Type 1. Both are "Prizewinner" level Irish dancers.

## Champion Children (cont.)



### Andrew Frye

Nominated by Sarah Dionne

Andrew was diagnosed with Hydrocenphalus when I was five months pregnant, either my uterus had a stroke, or he had a stroke while in the womb. Doctors said that Andrew wouldn't live past birth, and then he was given a 5-year life span to live. Today, Andrew is a strong 10 year-old boy, still fighting and beating many odds.

### Katrina Gadwah

Nominated by Astrid Wielens and Zebra Crossings

Over the past five years, Katrina has navigated her life journey with asthma, juvenile rheumatoid arthritis, digestive issues, and food allergies. There have been times of prolonged illness. Regardless of the number of times she is left feeling sore and fatigued, she always rebounds with a smile and an openness to life and true appreciation for simply having a "good day." Often Katrina steps into mentoring roles, providing extra care and encouragement to others. As one speaks with Katrina, you would never know the hardship that she has faced. Her positive attitude, perserverence, and resilience are inspiring.



### Matthew Garrett

Nominated by Allison Daigle, RN

Matthew represents the true meaning of perseverance. Not only has Matthew met with physical limitations, he has had times of extended absences from school and his friends.

Matthew chooses to attend school as much as possible with a love for learning and cheerful attitude. One cannot help but smile when meeting Matthew. He is an inspiration to us all.

### Sugei Gonzalez-Hernandez

Nominated by Laurie Fleming

Sugei was born premature and has complications related to being born so early. She suffers from asthma and paralysis of the vocal cords and cannot speak above a whisper. She also manages feedings through a tube daily. Despite having all of these physical impairments, Sugei is well known and loved in our school. She is friendly to all students and she has a good attitude. She participates fully in her program, and she is an important part of our school community. She has continually shown progress and independence in her daily activities. We are proud of Sugei!

