



**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)



Bob Quinn, Chair of the CYCC, presents Ryen Blackey with an award at the annual childhood chronic conditions awareness event.

“The percentage of children with chronic health conditions is on the rise, and new research being presented at the Pediatric Academic Societies 2016 Meeting shows this is especially true among children who live in or near poverty.”

– American Academy of Pediatrics



## Council for Youths with Chronic Conditions 2016 Annual Report

“Facilitating Inspirational Change”



As a teacher, I’ve seen it with my own eyes. The ravages of poverty on the minds and bodies of my students. It is now becoming abundantly clear the link between poor health and poor kids. I’ve also seen – especially as my former students have grown to adulthood – that small efforts can go a long way in changing a child’s life. But these one-on-one efforts are too little to turn combat the overwhelming trend.

According to the US Census, In New Hampshire has seen the poverty rate among children nearly double since 2000 – from 6 percent to 11 percent. That’s 28,000 children, but that measure is somewhat outdated and arbitrary. In schools around the Granite State, there are 46,700 children who are eligible for free and reduced lunch.

We don’t know exactly how many of these children have chronic conditions but there are approximately 42,000 – one out of every six children who have a chronic condition. What is clear is that – having a child with a serious health problems puts families in an economic bind– caused in part by uncovered medical expenses and missed work. Since few families have access to emergency financial resources – this means having a sick kid can lead to economic hardship, instability and even poverty.

This concern has become our focus and that’s why in 2016 we have advocated for better understanding of our families and their struggle. We have joined many of our partners to look beyond our individual policy silos and begin to consider the growing opportunity gaps that afflict our poorest children. The challenge of having a child with special health care needs is difficult but the demands are exponentially harder when strapped with limited resources and opportunities. In addition, too many of our families find their economic stability eroded by personal challenges and additional expenses relating to caring for their children.

The Council for Youths with Chronic Conditions mission statement is: “Facilitating Inspirational Change.” We are a small, parent-member state council that is the voice for families of children with chronic health conditions. We believe that New Hampshire needs to invest in our children and ease the burden on our families. That is why we brought a nationally recognized expert to New Hampshire to provide testimony to policy makers and advocates about the benefits of the New Hampshire Health Care Protection Plan. We’ve also convened meetings with partner advocates to listen to and assist them. Our voice is larger when join together.

2016 was an important year as we continued to grow, put our mission statement into action and sharpened our focus around a few core principles. Among them: Create a communication network for our partners and stakeholders. Raising awareness of the policy challenges and personal successes of our families. Supporting initiatives that serve our families. Finding our place and organizing ourselves to meet our goals has caused us to look hard at our organizational structure. We continue to revised our operations to be more efficient, focused and proactive. As a result, we have increased our ranks to include new council members. We’ve also created new initiatives, while building on our signature “Champion Children” annual awards luncheon. In short, we can’t make the diseases or conditions go away; but we can improve life for sick kids and struggling families. We are small but when we personalize our efforts; we can make a big difference in a child’s life.

Sincerely,  
**Jeff Woodburn**  
Executive Director

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

– Harry Truman

## Champion Children (cont.)



### Emily Pepino

**Nominated by Jennifer Franz RN**

Emily was diagnosed with CRPS at the age of 11. She advocated at the NH State House for awareness for the condition and participated in the NSTAR walk for Boston Childrens Hospital for two years, raising money for research. The first year she was made a “miracle maker” for raising over the limit she was required to raise. Emily’s dream is to become a nurse practitioner so she can help children and adults like her. She has a great deal of empathy and understanding of others with chronic health conditions and wants to make a difference in this world.

### Nicholas Plourde

**Nominated by Chantel Vaillancourt**

Nicholas should be commended on how he has handled the extremely difficult news of being diagnosed with leukemia, right from the get go Nick was very communicative with the school regarding missed classwork, as his academics are of the utmost importance to him. Nick and his family displayed a positive attitude, mature decision making, and an unshakable poise in the wake of devastating news. I am happy to report that Nick is in full recovery and back at school earning an “A” average in his academic classes. Nick is admired by his peers, and academic staff at Pinkerton Academy for his tremendous strength and perseverance.



### Mia Rose Quigley

**Nominated by Jill Prakop**

Mia is the epitome of courage. Every day she experiences the pain of living with ulcerative colitis. Mia is an incredibly courageous, strong, resilient 8-year-old. She has handled her illness with grace, humor, and a level of self-assurance that is remarkable and admirable in one so young. Ever since she was diagnosed at 3 years old I’ve never seen her complain or cry about her illness. Mia’s level of maturity and courageousness is inspiring. She is a true champion!



### Hannah Smith

**Nominated by Joyce Bernier**

Hannah Smith has a love for life that goes well beyond a typical 11-year old and she tackles each and every challenge that comes her way with a courageous spirit and positive attitude. Despite all the hardships she faces she continually gives to others, has a keen sense of understanding, can identify quickly when someone needs help, encouragement, or at times just a hug; she touches the lives of those young and old, with her ability to comfort, heal and help those who are less fortunate and asks nothing in return. Hannah’s personality lights up a room, fills it with love, compassion, and kindness; something we should all aspire to.



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

**January, 10th**

**Tuesday – 6 pm**

*Upham Walker House, Concord*  
Regular Meeting

**April 12th**

**Wednesday – 10 am** (tentative)  
Meeting and Tour

**May 10th**

**Wednesday – 6 pm**

Annual (Budget, Elections) Meeting

**September 13th**

**Wednesday – 6 pm**

*Upham Walker House, Concord*  
Regular Meeting

**November 15th**

**Wednesday – 11 am**

*Holiday Inn, Concord*  
“Champion Children” awards ceremony (lunch included)





CYCC has long provided support to camps that provide services to youths with chronic conditions. CYCC Executive Director Jeff Woodburn and Zebra Crossing's Executive Director Astrid Wielens are with children at Camp Spinnaker.

## Champion Children (cont.)



### Jaya LaBour

**Nominated by School Nurse Mary**

Jaya Labour is a 14-year old student who lives fully with a life-threatening allergy to eggs, chronic Lyme disease with co-infections and "Pediatric Autoimmune Small Fiber Neuropathy". He continues to receive intensive therapy for his conditions, but still keeps up with his school work. Jaya is compassionate, sensitive, determined and strong and very deserving of an "Out-standing Adolescent" Award.

### Katherine McCann

**Nominated by Anne Burke**

Although Katherine is one of the most intelligent and accomplished students in her class, she is also humble and always ready to help her peers. She is a positive presence in the classroom and a leader in our school. Katie's gifts in the field of technology, along with her initiative and organizational skills, have resulted in Souhegan's first Computer Programming Club, of which she is the founder and president. She has also engaged in a program outside of school called Hour of Code, which teaches students how to write computer code. Furthermore, she is on track to receive her Gold Award with the Girl Scouts of America this year. Ever polite, gracious, and grateful for any help or advice, she is the ideal student and a model for others.



### William Nolet

**Nominated by Janet Moffett**

William is truly an inspiration to all and a true hero! His life has changed dramatically after being diagnosed with Type 1 Diabetes. Through it he has shown an impressive level of maturity maintaining good spirits and a sense of humor along the way despite this major life change. William is involved with his care 110% and has an amazing understanding already about Diabetes and what it is and what it is not. William figures out most of his care at school and all the steps involved in giving himself his shot of insulin.



## 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.



Emily Pepino with members of CYCC, Miss New Hampshire, and family as she receives one of the "Champion Children" awards.

## 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 resilient.
- ▶ Promote and support improved healthcare options, access to care and services.

## Council for Youths with Chronic Conditions

|                              |  |
|------------------------------|--|
| Robert Quinn                 | Concord, Chair   |
| Joelle Martin                | Milford, Vice Chair                                    |
| Sarah Aiken                  | Concord, Treasurer                                     |
| Lisa DiMartino               | Gilford, Secretary                                     |
| Paula Garvey                 | Amherst  |
| Michael Dennehy              | Bow  |
| Loretta McGrail              | Rochester  |
| Michael Rollo                | Rollinsford  |
| Ann Emmerling                | Goffstown  |
| Sen. Andrew Hosmer           | Laconia  |
| Rep. Stephen Schmidt         | Wolfeboro  |
| Mariellen J. MacKay          | Nashua   |
| Nancy Wells                  |  |
|                              | Department of Education                                |
| Maggie Dolfini               | Brookline  |
| Elizabeth Collins, RN-BC, MS | Health and Human Services,<br>Special Medical Services |



Allan Bergman is a nationally-recognized leader in influencing the development of policy relating to "best practice" services and supports for people with disabilities and special health care needs. Mr. Bergman has been invited to Concord to provide education on the NH Health Protection Plan (Medicaid Expansion) as well as training to advocates.



CYCC works with many partners including, Spark, an early childhood advisory council. Spark hosted a legislative lunch that outlined policy goals for the next five years.

## History and Composition



Christopher Kennedy, Government Affairs Director, NH Healthy Families accepted the Champion for Children Business of the Year from the Council for Youths with Chronic Conditions. From the left is Miss NH Caroline Carter, Mr. Kennedy, CYCC Chair Bob Quinn and CYCC Executive Director Jeff Woodburn. The award was presented at the CYCC's annual childhood chronic conditions awareness event.

The Council for Children and Adolescents with Chronic Health Conditions (CCACHC) dates back to 1993 and an Executive Order of then-Governor Stephen Merrill establishing an "Advisory Council" 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-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,

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.

In 2013, the council's name was changed to the Council for Youths with Chronic Conditions (CYCC).

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

## Council's Purpose

Raise Public Awareness  
Improve Public Policy  
Support Local Initiatives And Pilot Projects

## Champion Children (cont.)



### Luke Dorow

#### Nominated by Astrid Wielens

Luke is a wonderful, kind and caring 9-year-old who has multiple diagnosis including asthma, Lyme's disease and PANDAS (Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections). These conditions affect him daily. Luke shows strength and resiliency as he adapts to various environments and the unpredictability of his health condition. He remains positive and empathetic towards others. He absolutely loves exploring nature and is determined to keep trying new experiences and challenging himself. Luke is a worthy Champion Child and positive example for other youth.

### Emalie Harrington

#### Nominated by Christina D'Allesandro

Emalie Harrington is a true inspiration. She was born with many complex needs and has spent too many days of her life at Boston Children's Hospital. Emalie struggles with hearing loss, metabolic issues, severe cardiac impairments, communication and mobility restrictions. She's is the girl who many said would never walk or communicate, now Emalie is walking and running faster every day without assistance. She is a talking machine and can read and write words and do simple math.



### Olivia LaPorte

#### Nominated by Jessica Tuttle

Olivia is a driven, committed, hardworking, but most importantly giving and selfless individual, Olivia is most proud of raising money to help children living in orphanages due to HIV/AIDS epidemic, helping in schools in South Africa and Fiji, and visiting senior citizens in Australia. Olivia has gone above and beyond to educate herself in other cultures and countries, manage her own pain and medical appointments, and still manage to be an A average student. She is admired and respected by all who meet her and will be one of those individuals that makes changes in others' lives!

“My life changed 13 years ago when my son Liam was born with Down syndrome. I view life differently, not because of challenges but because every milestone in my son's life is highlighted with great celebration. Liam has taught me to love people for who they are.”

- Michael Dennehy, Bow



Tour of the Monarch School of New England in Rochester. Jeff Meyers, Commissioner of Health and Human Services, Monarch School leaders Kate Sisneroz, Director of Education and Kathy Moses, RN, Director of Nursing along with CYCC Executive Director Jeff Woodburn toured the Monarch School, a day school that serves children ages 5 – 21, with significant physical, medical, developmental, behavioral and emotional disabilities.



Members of the CYCC annually take a tour of facilities that impact child and families with chronic conditions. In 2016, we visited Massachusetts General Hospital and learned about their Pediatric Palliative Care Service.

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 2016 winners.



Laurel Auth  
Nominated by Anne Burke

Not only is Laurel a conscientious student, but she is also a kind and caring individual. As someone who has had to overcome obstacles over the past several years, she has shown tremendous growth and resilience over the course of her high school experience.

In the future Laurel plans to study psychology in college and eventually become a school counselor. Given her natural empathy and compassion for others, she is making a good choice.

In addition, her solid work ethic and resourcefulness, as well as her willingness to help others—such as babysitting for a family in need and participating in the local "68 Hours of Hunger" project—bode well for her future contributions to her community and profession.

Ryen Blackey  
Nominated by Mary Mirkin

Ryen is a champion due to his amazing resilience despite having several significant medical conditions which have resulted in numerous surgeries and impaired mobility. Ryen is a well-respected member of his class at Interlakes High School in Meredith where he has achieved academic success despite his many surgeries. Ryen works hard every day to ensure that his chronic medical conditions will not prevent him from leading a full and productive life.



Caleb Brooks  
Nominated by Joyce Bernier

Caleb is very charismatic and funny, he is patient and lives life with a positive attitude. Caleb can lighten up your day with his optimistic outlook or even with just a simple smile; and although there are many things he cannot do he will always give it his best. Despite the issues that Caleb faces on a daily basis he is always strong willed, happy, and determined to encourage and uplift those around him.

Raise Public Awareness

We seek to amplify the voice of families of children 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. Governor Maggie Hassan declared the second week in November as Childhood Chronic Condition Awareness Week in New Hampshire. The Governor asked NH citizens to celebrate the week by promoting healthy lifestyles changes and encouraged people to become educated about chronic disease prevention, awareness, and management. Miss New Hampshire Caroline Carter, who has Diabetes, served as the honorary chairman of the week. A kick-off event was held in Concord with a special proclamation made by Governor Maggie Hassan, who is a parent of a child with special health needs and former member of the Council. Thirteen children were presented the "Champion Children" award. Parent advocates Heather Donnell and Audrey Gerkin were selected as the "Champion for Children" advocacy award and Centene/ NH Healthy Families, was the recipient of the "Business Leadership Award" for their contributions to help local families. News articles highlighting important contributions, high-profile success stories and issues of concern have been published in newspapers and magazines throughout the state and on our website, [www.nhcycc.org](http://www.nhcycc.org).

To understand the needs and learn about the accomplishments of children and their families, our Executive Director attended dozens of regional meetings to meet first hand with parents, school officials and medical personnel and care-providers. Each year the CYCC members conduct an educational tour that expands our network and knowledge about services available to families with children with chronic conditions. This year we visited Massachusetts General Hospital and learned about their Pediatric Palliative Care Service.



Disability activist Ken Jones presents CYCC Executive Director Jeff Woodburn with a cross-hatched handicap access aisle sign that was a project funded by the NH Lions Clubs.

The target audience of this effort has been parents, caregivers, government leaders and healthcare professionals and the general public.



Parent advocates Heather Donnell and Audrey Gerkin were selected as the “Champion for Children” advocacy award at the CYCC’s fall luncheon. Heather and Audrey were chief advocates for the bill to create a study committee to study pediatric nurse shortages and later co-chaired the legislative study committee that produced legislation to address this problem.

## Improve Public Policy

We were established to advise policy-makers on issues important to families with special health care needs. While we don’t lobby, the work of the governor, legislature and administration is important. Our legislative members – Senator Andrew Hosmer, of Laconia and Rep. Stephen Schmidt, of Wolfeboro, have been strong supporters and very helpful to us. Through our strategic planning session last year, we focused our policy work around facilitating information and policy guidance to our disease and condition partners. This group meets informally over breakfast to build coalitions, coordinate strategy and pass on information.

We also provide basic government resources to partner organizations. We arranged two days of meetings with Allan Bergman, nationally recognized leader in influencing the development of policy relating to “best practice” services and supports for people with disabilities and special health care needs. He also provided educational information on the benefits of the NH Health Protection Plan (Medicaid Expansion) to policy-makers.

The CYCC is key a member of the oral health care initiative to expand care sponsored by the PEW Foundation. In 2016, 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.”

## Support Local Initiatives & Pilot Projects

Our goal is to support local initiatives that provide unique services, programs and activities to children and families with chronic health conditions.

Once again, we supported summer camps with financial assistance that allows children with special health care needs to have this experience. After years of supporting Easter Seal’s Camp Snow-Mo, the CYCC entered a formal relationship as sponsor of their annual snowmobile “ride-in” program, where snowmobile groups compete to raise money for this camp. Over the summer, CYCC Executive Director Jeff Woodburn toured two camps: Camp Snow Mo, in Gilmanton Ironworks and Camp Spinnaker in Tuftonboro. We also were the critical link and provided funding to bring Zebra Crossing’s programming.

In addition, the council inaugurated a new “spirit award” that recognizes and makes a donation to a small, very personalized, local charity that focuses on public awareness activities in line with the CYCC’s mission. The first recipients are Hope for Guy, a Peterborough-based organizations committed to supporting and educating people about Duchenne Muscular Dystrophy and Think John Bradley, a Laconia-based charity that raises awareness and assists families combating Diffuse Intrinsic Pontine Glioma (DIPG). Both organizations were started by dedicated parents and family members who actively demonstrate concern and commitment to serving others afflicted with these diseases.

## Award-winning essay



Jeff Woodburn, Executive Director of the Council for Youths with Chronic Conditions, presents a plaque to Danielle Schillereff, of Wolfeboro, a 13-year-old Kingswood Middle School student, who was honored at a school assembly on Friday. Danielle was one of the 3 state-wide winners of an essay contest sponsored by the CYCC. She wrote about being inspired by an 8-year-old boy who has diabetes.

The word “disability” can be put in many different perspectives. One person may think of it as something that limits a person’s movements, senses, and activities, while another may think of it as something that decreases a person’s self-esteem, and lowers them below everyone else. I think of this word differently. When I think of “disability,” what comes to mind is someone who is strong, brave, and courageous. These three words are what describe an eight-year-old boy named Nicholas, who suffers from a chronic health condition called diabetes. Nicholas was first diagnosed with this condition when he was seven years old. From that point on, he had to test his blood sugar at least ten times a day, by pricking the tip of a chosen finger. His blood sugar level is very crucial to his condition. If this lowers, Nicholas has to be given a certain amount of carbohydrates to raise it until it reaches his target zone. If it rises, he has to be given what is called an insulin shot. This is injected into his arm and stomach area to lower his blood sugar. This is also used every time Nicholas eats. Without it, his blood sugar would increase. Nicholas needs to count the amount of carbohydrates in the food he eats, to determine how much insulin he needs. No matter which direction his blood sugar goes, it is extremely dangerous to his health. If he is not being watched carefully, Nicholas could slip into what is called diabetic coma. This is caused by his sugar levels being too low for his body’s needs.

Everywhere he goes, his diabetic kit goes along with him. This contains all his diabetic necessities including what’s called glucagon, which is used to treat extremely low blood sugars. Nicholas is tested once or more during the night for his blood sugar. He has become so familiar to the sense of a shot, that Nicholas does not even wake for it. Now he lives his everyday life fearless of feeling the prick of a needle. Nicholas has not only shown me how brave he can be, but how much he has overcome. When I first met Nicholas, he seemed to act and live like everyone else, but I now see that he’s not like that. He’s special, and has taught me not to fear small things in life, but to acknowledge the ones such as his condition. To Nicholas it is no longer a fear, but a battle that has been conquered. I am proud to say that I know Nicholas, and that I am friends with him. At the age of eight, he teaches his fellow classmates about the struggles, and obstacles, of diabetes. He has also touched the hearts of many adults as well, in ways that only someone who is truly fearless, and strong, could do. I know that Nicholas has inspired many people, and will inspire many more along his path, with his strength, bravery, and courage.

by Danielle Schillereff  
13 year-old Wolfeboro resident

The CYCC participates in the following organizations that promote expanding opportunity for children:

- NH Kids Count
- Our Kids NH
- NH Endowment for Health
- NH Listens.

Several members of the Council participate in a day-long training hosted by Boyle Community Pediatric entitled Bridges out of Poverty training.

**“When I think of “disability,” what comes to mind is someone who is strong, brave, and courageous. These three words are what describe an eight-year-old boy named Nicholas, who suffers from a chronic health condition called diabetes.”**