Council for Youths with Chronic Conditions
2015
Annual Report

"Facilitating Inspirational Change"

Rare Disease Day was commemorated at the State House CYCC's Jeff Woodburn presents a resolution to event organizer, Jamie Plourde, who has Friedreich's ataxia, a rare genetic disease.

As a teacher, I've seen it with my own eyes. One person can change a kid's life. It's that simple, but far from easy. **The Council for Youths with Chronic Conditions** aims to encourage that change by making the right connection with the right person at the right time. Our 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. 2015 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've revised our by-laws to better accommodate our parent-members' very hectic schedules by limiting the number of formal meetings and creating ad-hoc committees to focus on priorities. As a result, we have increased our ranks to include four new council members. We've also created new initiatives, while building on our signature "Champion Children" annual awards luncheon.

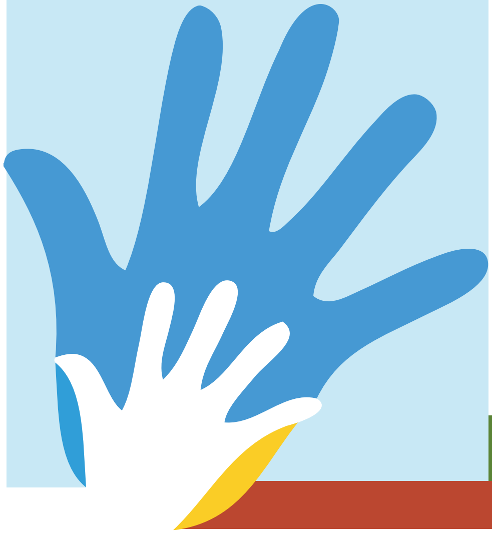
We have joined many of our partners to look beyond our individual policy silos and begin to consider the growing opportunity gaps that afflict our poorest children. The challenge of having a child with special health care needs is difficult but the demands are exponentially harder when strapped with 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.

Stefany Shaheen was the chair of our annual Childhood Chronic health conditions awareness week.

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

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



Council for Youths with Chronic Conditions

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Barbara Richardson	Concord, Vice Chair
Paula Garvey	Amherst, Treasurer
Michael Dennehy	Bow, Secretary
Loretta McGrail	Rochester
Corry Hughes	Jefferson
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Heather Gagne	Department of Education
Elizabeth Collins	RN-BC, MS, Health and Human Services, Special Medical Services
Alicia M. L'Esperance	Health and Human Services, Partners in Health
Laurie Fleming	RN Derry
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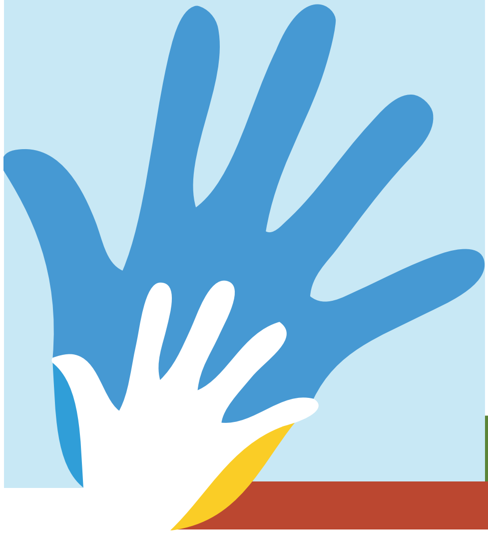


Who We Are:

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.

The family of Rosie Garvey are with her 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.

History and Composition

Leaders gather at the CYCC's annual "Champion Children" awards luncheon. From the left is Sen. Lou D'Allesandro, Boston School Committee Member Regina Robinson, CYCC secretary Michael Dennehy, author and diabetes awareness advocate Stefany Shaheen and CYCC council member Sarah Aiken.

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).

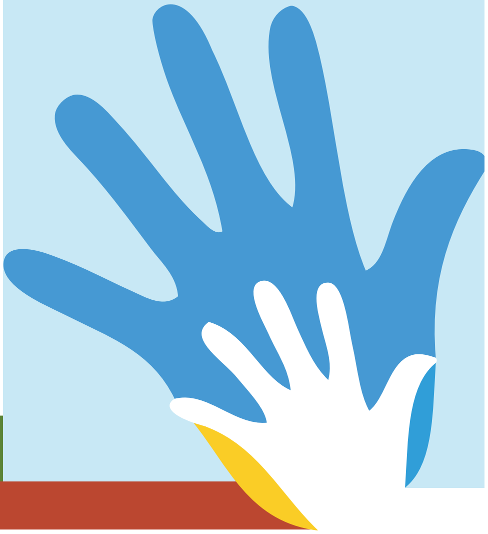
This Council is the only statewide organization that has a legislative mandate to focus on the issues affecting children and adolescents with chronic health conditions.

Council's Purpose

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

Working with elected officials. CYCC Executive Director Jeff Woodburn and March of Dimes Director of Program Services Abby Rogers met with US Sen. Kelly Ayotte while in Washington, DC to update her on policy matters of importance to both organizations.

Boston School Committee member Regina Robinson, a parent and advocate for children with special health care needs, spent a day touring New Hampshire. She met with parents, advocates, elected officials and visited Bow High School. Robinson is shown with Bow's Superintendent of Schools Dean Cascadden.



Former CYCC chair Bill Smith, of Concord, received the "Champion for Children" award for his unyielding advocacy for children with chronic conditions. His son, Jack, holds up the award.

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

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 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.

Stefany Shaheen, a parent, author and advocate for diabetes research and awareness, 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. Fifteen children were presented the "Champion Children" award. Former CYCC Chair Bill Smith was selected as the "Champion for Children" advocacy award and Bank of New Hampshire, of Laconia, was the recipient of the "Business Leadership Award" for their contributions to help local families.

CYCC also arranged a day-long tour for Boston School Committee member Regina Robinson, a parent advocate for children with special health care needs, to share her experiences with parents at a Manchester breakfast forum, young people at our "Champion Children" awards luncheon in Concord, and elected officials and policy-makers at a State House policy briefing. Robinson also got a tour of Bow High School.

In addition, we hosted our second annual essay contests, where New Hampshire youths from grades 5-8 wrote an approximately 500-word essay about a child with a chronic condition that inspired them. Three students -- Danielle Schillereff, of Wolfeboro, Isabel Dreher, of Peterborough , and Mikayla Cadorette, of Chichester, were honored with a plaque and received a $150 prize.

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.**

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 went to Dartmouth Hitchcock's Children's Hospital (CHaD). We've also worked with various partners on shared projects like a tour of Elliott Hospital's (NICU) New Born Intensive Care Unit with Governor Maggie Hassan and the March of Dimes local leadership.

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. Sen. Hosmer, a member of the Senate Finance Committee, provided a State Budget briefing at our annual meeting. Along with the School Nurses Association, state Department of Education and state Health and Human Services, we provided information to support funding for the re-establishment of the School Nurse Consultant position, which provides vital information and best practices to school nurses around the state.

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

In 2015, we became more formally involved 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 three camps: Camp Snow Mo, in Gilmanton Ironworks; Joni & Friends Family Retreat and Camp, in Greenfield and along with Governor Maggie Hassan Camp Spinnaker in Tuftonboro.

We also were the critical link and provided funding to bring Zebra Crossing's programming to children enrolled in the Seacoast Partners in Health program, sponsored a participant in the UNH Leadership Series and made a contribution to supported programs at Dartmouth-Hitchcock's CHaD in memory of Benjamin Quinn, our board chairman's son.

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 organization were started by dedicated parents and family members who actively demonstrate concern and commitment to serving others inflicted with these diseases.

The CYCC supports the work of Joni & Friends Family Retreat Camp, a faith-based program for families and children with special health care needs at the Barbara C. Harris Camp in Greenfield. CYCC's Jeff Woodburn is with Program Manager Liz Babbitt and campers.

CYCC is proud to be a contributing partner to Camp Sno Mo. Easter Seals NH and the Daniel Webster Council, Boy Scouts of America work together to create this nationally-recognized, residential camp program, sponsored by the New Hampshire Snowmobile Association to create a life-changing experience for campers. Located in Gilmanton Iron Works, NH, children and young adults with disabilities and special health care needs, ages 11-21, can inclusively participate alongside Boy Scouts in a wide variety of activities. CYCC Executive Director Jeff Woodburn is with Webster Council's Camping Director Mark Callahan and Camp Sno Mo Director Robert Kelly.

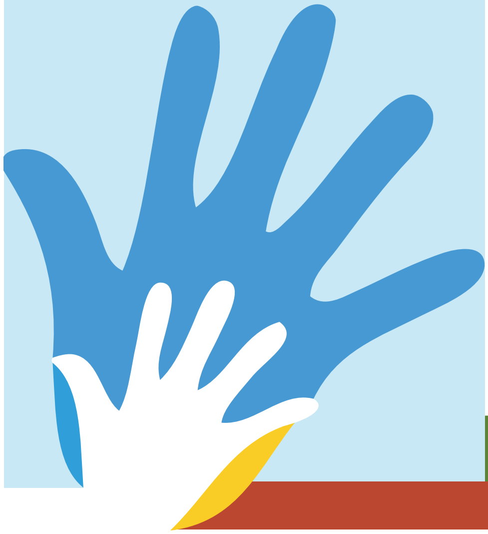
Governor Maggie Hassan toured Camp Spinnaker, for young people with diabetes. She is with Astrid Wielens, of Zebra Crossings, and other advocates.

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.”*



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, 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

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 2015 winners.

Thomas Viana

Nominated by Laurie Fleming, RN

Thomas is my hero every day! Despite constant seizures, paralysis on one side and being in Boston hospital 3 out of every 4 weeks, Thomas is usually always cheerful and has a good rapport with his fellow students. He is a very caring individual. Thomas puts a lot of effort and hard work into his schooling. He is very loving.

Natalie Smith

Nominated by Kerri Reynolds BA, RN

Natalie is a courageous person who deals with adversity gracefully. She is a champion not only for chronic disease awareness but also for people who need a voice. Engaged in her community, Natalie is a friend to all that she meets.

Isak Ahlgren- McCune

Nominated by Adam McCune

Isak has become a champion for having spent 4 years battling his symptoms and sometimes those that were sought to treat him. When he was finally diagnosed his entire trajectory changed. Today, Isak is still battling symptoms, but the video of history has been seen more than 27,000 times and continues to be shown to doctors and parents around the world. He has become a face for his disorder.

Colin Pynn

Nominated by Mary Arrowsmith, RN

From the day I first met Colin I was most impressed with his positive demeanor and competence. He is realistic, respectful, responsible and most reliable. He always has a smile on his face and although he has had Diabetes since first grade, he never lets it interfere with his life, while taking it seriously.

The CYCC works with many partners to advance important policy and awareness priorities, including the Partnership to Fight Chronic Disease. Dr. Ken Thorpe, the executive director of the partnership, CYCC Executive Director Jeff Woodburn and Heather Carroll from the Alzheimer's Association, joined Laura Montenegro on NH1 Community on 99.1 NH1 News Radio for a program on chronic health conditions.

Champion Children (cont.)

Rose Correll

Nominated by Kerry Smith

Rose has an unwavering commitment to bettering her community --- for children and teens with chronic health conditions. From serving on the Muscular Dystrophy Association Camp Teen Council to working with Illumina Labs to promote access to whole genome sequencing for teens like herself, Rose uses her diagnosis as fuel to change the world. Rose is a creative, well-spoken and effective advocate, but is also a warm, quick witted and fundamentally kind young woman.

Kalie Patenaude

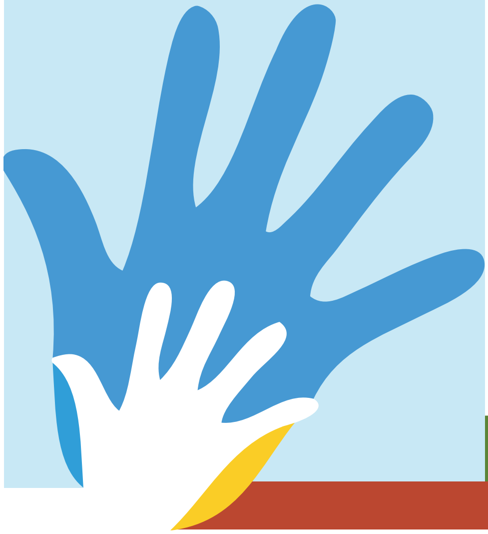
Nominated by Ashley Hodge

Kalie is like the brightest star that never fails to shine. Her positive energy and warm smile can be felt and seen constantly. Kalie is the first to help another child in need, she is a true champion.

Maggie Atkins

Nominated by Dr. Adam Weinstein, Terri LaRock and Anne Pickette

Maggie is a scholar, athlete and very involved in her school. She is friendly, kind, compassionate and positive role model. She has learned effective self-advocacy skills and is seen as a leader amongst her peers. She participated Camp Sunshine's "kidney and solid organ transplant week" Team Impact for the past two years. volunteered to be a part of a multi-institutional national study on Chronic Kidney Disease in children to help kids who develop chronic kidney disease in the future. ended, encouraged and advocated for peers coping with illness and injury within her community.



> "*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***

Champion Children (cont.)

Parish Mahoney

Nominated by Rob Kelly

Parish is always looking to overcome his disability but at the same time not allow it to stop him doing anything he sets his mind to. His determination and drive is one that is not uncommon with this population, but Parish takes it to a whole new level. Parish is one of the most generous, emphatic, and courageous young men I know and I am delighted he chose to spend his first-ever overnight camp experience at Camp Sno-Mo this past summer.

Rosie Garvey

Nominated by Anne Burke

I've long admired Rosie for her pleasant disposition, her outstanding academic performance, and her grit in the face of adversity. She's treasure in the classroom in terms of engagement and collaborative work with her classmates. Yet, despite the discomfort, the time-consuming daily treatments, and the disruption caused by a plethora of unavoidable medical appointments, Rosie remains uncomplaining and steadfast in achieving her academic goals, never taking shortcuts and only using minor accommodations. She's also involved in fund-raising for CF research. In short, Rosie truly is the exemplar of an individual who has overcome enormous obstacles; she represents our best both as a student and as a person.

Trey and Ellie Delworth

Nominated by Astrid Wieliens

"Team Trellie" is how we were introduced to Trey and Ellie Delworth when They were 6 years old with open mind and positive energy. Trey's exuberance and kindness have remained constant through his journey. He has grown from a child who was just learning about his health condition to one who manages it, allowing him to play on competitive soccer teams. Trey's determination is inspiring. It's quite common that siblings of children who have a chronic health condition feel that their sibling "gets all of the attention." All Ellie has ever demonstrated towards her brother is love and support. Moreover, she rarely reveals her own condition, allowing her brother to have all attention. Ellie's gentle

CYCC's Jeff Woodburn and Abby Rogers presents a donation to CHaD's Sharon Brown in the memory of Benjamin Quinn. Abby Rogers is Ben's mother.

2016 Meeting Schedule for the Council for Youths with Chronic Conditions

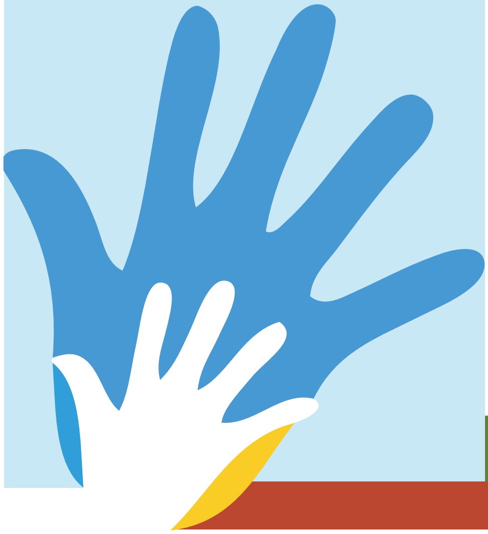
January, 12th
Tuesday – 6 pm
Upham Walker House, Concord
Regular Meeting

April 19th
Tuesday – 10 am
Meeting and Tour

May 10th
Tuesday – 6 pm
Upham Walker House, Concord
Annual (Budget, Elections) Meeting

September 13th
Tuesday – 6 pm
Upham Walker House, Concord
Regular Meeting

November 16th
Wednesday – 11 am
Holiday Inn, Concord
"Champion Children" awards ceremony (lunch included)



Champion Children (cont.)

Trey and Ellie Delworth (cont.)

ways make it easy for any child to be with her. She makes everyone feel good about who they are and she is always quick to lend a hand.

Mckenzie Rowbotham

Nominated by Margaret Duffy

Mckenzie uses her experience living with arthritis to make a difference in the lives of others facing the daily challenges of arthritis. Through her meetings with the NH Congressional delegation she has shined a spotlight on the impact of arthritis and worked for better access to medication and specialists, and more arthritis research funding. As an Arthritis Foundation advocate, Mckenzie has become a strong, confident, and passionate voice and face of arthritis.

Bryce Haines

Nominated by Janet Moffett, RN

Bryce's life was turned upside down. Instead of having a fun summer running around and playing with friends, it was filled with treatments, procedures, long drives, various medications, chemo, uncomfortable side effects and fatigue making him unable to participate in many of the things he likes to do. Bryce has been a very courageous boy meeting all of the challenges before him with bravery and courage.

COUNCIL FOR YOUTHS
WITH CHRONIC CONDITIONS
Facilitating inspirational change.
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