



nh cycc

Council for youths with chronic conditions

2023

Annual Report



Preface

This Annual Report is compiled in compliance with RSA 126-J:5. It contains general information pertaining to progress being made to reduce barriers in obtaining effective community and family-based services and support, and efforts on the part of the Council to educate and collaborate to improve the capacities of communities to respond to the needs of families with children and youth with chronic health conditions.



New Hampshire Council for Youths with Chronic Conditions

25 Old Dover Road Rochester, NH 03867

www.nhcycc.org

info@nhcycc.org

Report prepared by Leah Stagnone, Council Director

Council Members

<i>Name</i>	<i>Position</i>	<i>City</i>
Karen Livernois	Chair/Parent Appointed by Governor	Londonderry
Deodonne Bhattarai	Vice Chair/Parent	Concord
Tim Guidish	Treasurer/Parent	Merrimack
Kristin Bonny	Secretary/Parent	Barrington
Michele Caswell	Parent	Raymond
Regan Lamphier	Parent	Nashua
Nicole Parker	Parent	Tamworth
Karin Mortimer	Parent	Merrimack
Lauren Sirignano	Parent	Campton
Jennifer Burbank	Parent	Danville
Thaiadora Dorow	Parent	Derry
Recent Vacancy	Youth Member	TBD

NH State Advisors/Representatives/Appointed positions

DHHS: Deirdre Dunn Tierney

Community Based Agency Director: TBD

Education Department: TBA

Insurance Department: Josh Hilliard

NH House: Representative Katelyn Kuttub

NH Senate: Senator Becky Whitley

Professional/Community Organizations

NH Family Voices: Sylvia Pelletier

Epilepsy Foundation New England: TBD (transition in staff)

NH School Nurse's Association: Laurie Flemming (outgoing)

Council Director

Leah Stagnone

Who we are

The Council for Youths with Chronic Conditions (CYCC) is a parent-focused State council committed to being a voice for families of children with chronic health conditions. We educate and inform policymakers and stakeholders of the unique challenges and opportunities to expand access to affordable, quality health care, supportive work environments, and community-based services and to celebrate the resiliency of children and their families.

Our guiding principles include ensuring that our children and youth with chronic conditions have affordable access to care and supportive home and community environments, and that our families have supportive work environments.

Definition of a chronic condition

The Council for Youths with Chronic Conditions 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 Youths with Chronic Conditions is 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.

- Promote the organized assessment of the needs of children and adolescents with chronic conditions and their families.
- Serve in an advisory capacity to the Department of Health and Human Services, Department of Education, and Insurance Department for Policy and Program Development.
- Collaborate with the Department of Health and Human Services, the Department of Education and their public and other public and private organizations statewide to enhance community-based family supports that meet the unique needs of children and adolescents with chronic health conditions and their families.
- Increase awareness in the public and private sector of the medical, social and educational issues that impact youth/children with chronic health conditions and their families.
- Provide consultation and testimony to the legislature on related issues.
- The Council shall report annually on or before December 1st to the Governor and the General Court regarding the progress being made to provide services and support to youth with chronic conditions and their families in regular educational and medical environments allowing them to remain in or near their own homes and communities.

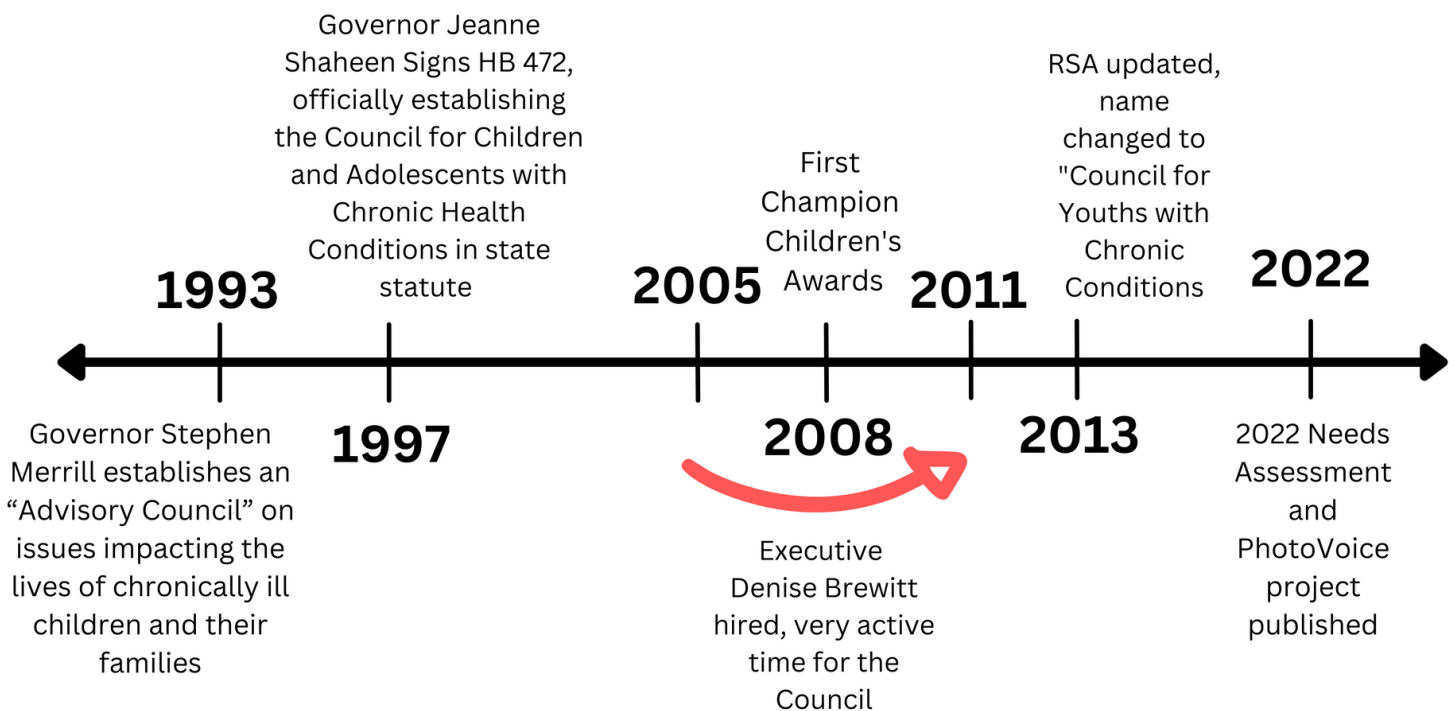
The members of our Council represent family experiences with a wide spectrum of chronic health conditions, including:

spinal muscular atrophy, cystic fibrosis, asthma, Ehlers-Danlos syndrome, dysautonomia, cerebral palsy, primary immunodeficiency, Apert syndrome, fetal alcohol syndrome, epilepsy, Rubinstein-Taybi syndrome, PHOX2B congenital central hypoventilation syndrome, neuroblastoma, DiGeorge syndrome, mast cell disorders, autonomic neuropathy, Cornelia de Lang syndrome, pediatric cancer, diabetes, kidney disease, PANDAS, cyclic vomiting syndrome, Lyme disease, and other genetic, immunological, and gastrointestinal conditions.

History

The Council for Youths with Chronic Conditions dates back to 1993, when it was known as the Council for Children and Adolescents with Chronic Health Conditions (CCACHC). 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. The signing of HB 472 by Governor Jeanne Shaheen in July 1997 officially established the Council within state statutes. Today, there are 15,000 youth in New Hampshire affected by chronic health conditions, who the Council keep in mind while educating and informing the public of their needs.

CYCC Timeline



2023 Council Activities

- **Ongoing since 2022:** The Council provided input on behalf of families to BCFS regarding the Title V redesign process.
- **Ongoing since 2022:** CYCC continued promotion of PhotoVoice project.
- **February 2023:** CYCC participated in a Bipartisan Disability Caucus legislative meet and greet, educating legislators about how policy can impact the lives of youths with chronic conditions.
- **March 2023:** Family of CYCC members testified at a hearing for HB 467, to provide education and understanding on the issue of playground accessibility.
- **March 2023:** CYCC Members Karen Livernois and Karin Mortimer presented to the NH Leadership Series about our Council and issues impacting youths with chronic conditions.
- **June 2023:** CYCC provided grant scholarships for NH summer camps including Camp Allen, Zebra Crossings, and multiple YMCA camps, with the objective of increasing camp inclusion for children with chronic health conditions.
- **June 2023:** The Council donated two Go Baby Go NH! cars for adapting and use by children with mobility restrictions.
- **July 2023:** CYCC worked with the Governor's office on Chronic Disease Day Proclamation
- **July 2023:** CYCC hosted our annual Kids Chronic Health Awareness Event at the McAuliffe-Shepard Discovery Center in Concord.
- **July 2023:** The Council established the Audrey Gerkin Leadership Award. This award acknowledges the Leadership that Audrey has brought to the CYCC by sponsoring Council members who want to complete the NH Leadership Series.
- **August 2023:** CYCC gave a presentation, hosted an information table, and showcased our PhotoVoice project at the 2023 Family Support Conference in Manchester.
- **September 2023:** The Council sponsored participation in the UNH Institute on Disability's New Hampshire Leadership Series for Council members Karin Mortimer and Kristin Bonny.
- **October & November 2023:** The CYCC Executive Council completed an extensive Council Director search process, ultimately hiring former Council Member Leah Stagnone to fill the role.

2023 Meeting Schedule for the Council for Youths with Chronic Conditions

January 18 - 5:30pm

Annual Meeting

Virtual, Zoom

March 16 - 5:30pm

Regular Meeting

Virtual, Zoom

May 17 - 5:30 PM

Regular Meeting

Virtual, Zoom

September 20 - 5:30 PM

Regular Meeting

Virtual, Zoom

November 15 - 5:30 PM

Regular Meeting

Virtual, Zoom



CYCC Celebration Event



CYCC Director Audrey Gerkin speaks onstage at the McAuliffe-Shepard Discovery Center

The Council for Youths with Chronic Conditions held our 2023 Annual Kids Chronic Health Awareness Event at the McAuliffe-Shepard Discovery Center in Concord, NH on Thursday, July 13th. We celebrated six Champion Award winners who demonstrate compassion and leadership within their communities. The PhotoVoice Project exhibit was on display, showcasing the creativity and lived experiences of youths with chronic conditions and their families.

We shared the stories of the Champion Winners with the attendees, and a Proclamation from Governor Sununu’s office was announced for July 10th as Chronic Disease Day. A slideshow presented some of the work from the year.

Activities Included:

- Catering from Uno’s Pizzeria and donated Stonyfield frozen yogurt sticks for dessert
- Discovery Center exhibits
- Arts and crafts table
- Photo booth with silly props
- Planetarium show
- Sensory room
- Spiderman live in-person
- Swag bags for youths attending



2023 Champion Awards

Champion Awards are given to a youths (under age 21) with chronic conditions who have shown extraordinary leadership in and/or commitment to their school and community.

Champion Amanda Conley

Amanda Conley, a student at Pinkerton Academy, is from Derry, NH. Amanda was nominated for the Champion Award by Laurie Fleming, representing the NH School Nurses' Association. Amanda has been a strong advocate for health promotion, self advocacy and the management of diabetes since she was in elementary school. She successfully petitioned the Derry School District to make nutrition information widely available for everyone to count carbohydrates of the food in the school nutrition program. Amanda offers mentorship services to middle school students with diabetes who may need some support and guidance.



Amanda Conley and family at the 2023 Kids Chronic Health Awareness Event

Champion Riley Logan

Riley Logan, from Gilford NH, was nominated for the Champion Award by Meg Jenkins. She has had to miss a great deal of school due to surgeries and rehabilitation associated with her diagnosis of Ehlers-Danlos Syndrome, but continues to strive for academic excellence, ranking in the top 10 of her class. Riley works with the school's Unified Club, assisting other youths with disabilities. To learn how to be an effective support person, she attended trainings provided by the Lakes Region Community Services Council. Riley is always looking out for the friend she assists, ensuring that she is included in activities in the community.



Riley Logan and family at the 2023 Kids Chronic Health Awareness Event

2023 Champion Awards

Champion Chase Stuber



Chase Stuber and family at the 2023 Kids Chronic Health Awareness Event

Chase Stuber, from Kensington, NH, began his advocacy in 2005, when he represented New Hampshire at the March of Dimes Corporate Office in Washington, DC. Chase later represented New Hampshire at the Speak Now for Kids Family Advocacy Day in Washington DC in 2019. In 2020, Chase and his family organized a donation drive for David's House and delivered approximately \$2,500 in needed goods. In 2021, Chase donated a special needs trike to Cedarcrest Center for Children with Disabilities for other students and friends to enjoy. Most recently, Chase and his family organized a 43 Mile Walk and Roll Challenge for Make A Wish America in 2023 and raised over \$1,000.00.

Champion Max Mendez

Max Mendez of Merrimack, NH was six years old when he was first diagnosed with cancer and founded the Mighty Max Mega Toy Drive. The toy drive has now continued for five consecutive years, collecting about 100,000 items for local hospitals and the David's House at Dartmouth. Max has participated in a variety of other fundraising events, including: the Jimmy Fund Walk, Alex's Lemonade Stand, Whip Pediatric Cancer, and the Kids Pan Mass Challenge. He has raised over \$50,000 for research and care with his participation. Additionally, Max has led other local fundraising initiatives for children who were diagnosed and relapsed with cancer, including lemonade and hot cocoa stands and summer toy drive collections.



Max Mendez and family at the 2023 Kids Chronic Health Awareness Event

2023 Champion Awards



Chase Stuber receives his award from Council members at the 2023 Kids Chronic Health Awareness Event

Champion Calvin Day

Calvin Day, a middle schooler from Somersworth, NH, was diagnosed with type 1 diabetes in 2nd grade. He competes in several sports, is active in fundraising for juvenile diabetes, and creates opportunities to educate his peers and teachers about the disease.

Champion Anna Mandh

Anna Mandh, a Champion Award winner from Hopkinton, NH, advocated in support of a NH legislative bill to create Children's Mobile Crisis units by testifying at the State House, as well as meeting with legislators and the media. She provided public input several times at school board meetings on this subject as well, encouraging other students to follow her lead. Anna is a donor to a children's group home, and has a goal to create a clothing and needs drive for inpatient youths. She has worked as a direct support professional since the age of 16, providing mentorship and care to a local teen with a disability.

Looking forward: Anticipated 2024 Activities

- New Council Director, Leah Stagnone, will be participating in a Learning Journey program with the MCH Workforce Development Center, and will travel to California for in-person training from March 4th-March 8th, alongside several team members from DHHS.
- In early 2024, the CYCC will participate in an annual disability meet-and-greet lunch with the state legislature, hosted by the Bipartisan Disability Caucus and the Disability Policy Roundtable.
- The Council looks forward to hosting our Annual Kids Chronic Health Awareness Event in the summer of 2024.
- The CYCC will continue to work toward implementing the goals established in our 2022 Needs Assessment report.
- The Council intends to explore the potential for setting up a Youth Advisory Council to the CYCC and otherwise increasing opportunities for youth involvement in the Council's work.
- CYCC will conduct outreach to families and stakeholders at chronic health and disability-related conferences and events, with the goal of building an email communications list, growing our family and community networks, and becoming a well-known resource to New Hampshire families impacted by chronic health conditions.
- The Council looks forward to participating in another Gubernatorial Town Hall on Disability and Chronic Conditions, in partnership with various New Hampshire nonprofit organizations, in the fall of 2024.
- CYCC will continue working to grow our Council, with a focus on increasing parent membership, establishing a new Youth Member, and inviting representatives from additional professional and community organizations.
- The Council plans to develop informational resources and webinars for New Hampshire families on topics relevant to youths with chronic conditions.
- The CYCC looks forward to growing our social media presence across new platforms, to connect with more New Hampshire families.



CYCC Chair Karen Livernois and Vice-Chair Deodonne Bhattarai at the 2023 Family Support Conference in Manchester, NH



Thank you to outgoing Council Director Audrey Gerkin!



Outgoing CYCC Director Audrey Gerkin with CYCC Chair Karen Livernois

CYCC has grown immensely under the leadership of Audrey Gerkin since 2021. This year, we say goodbye to Audrey as Council Director as she steps into a new role as a Systems of Care Specialist at the New Hampshire Department of Health and Human Services. Audrey brought a wealth of experience to the Council in areas including home and community-based services and disability policy. She is known for her work outside of the Council on the care workforce shortage, as well as for her facilitation of CYCC's 2022 Needs Assessment and PhotoVoice project. We know that New Hampshire youths with chronic conditions will continue to benefit from her expertise through her role at DHHS!

Introducing: Council Director Leah Stagnone

In November of 2023, Leah Stagnone stepped into the role of CYCC Council Director. Leah had previously served as the Youth Member of the Council for more than two years, and comes to the Council with a background in nonprofit disability and chronic illness advocacy. As a person with lived experience of chronic illness, Leah has worked to organize medical education events, promote public awareness, inform legislators, and compile resources for people in New England with rare and underrecognized chronic conditions. She looks forward to working on behalf of New Hampshire youths and their families in this new position.



Incoming CYCC Director Leah Stagnone