



nh cycc

Council for youths with chronic conditions

2024

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

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Report prepared by Leah Stagnone, Council Director

Contact Us & Learn More:

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Council Members

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

NH State Advisors/Representatives/Appointed positions

DHHS: Deirdre Dunn Tierney

Community Based Agency Director: TBD

Department of Education: TBA

Insurance Department: Jennifer Smith

NH House: Representative Katelyn Kuttab

NH Senate: Senator Becky Whitley

Professional/Community Organizations

NH Family Voices: Sylvia Pelletier

Epilepsy Foundation New England: TBD

NH School Nurse's Association: Emily Lajoie

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.

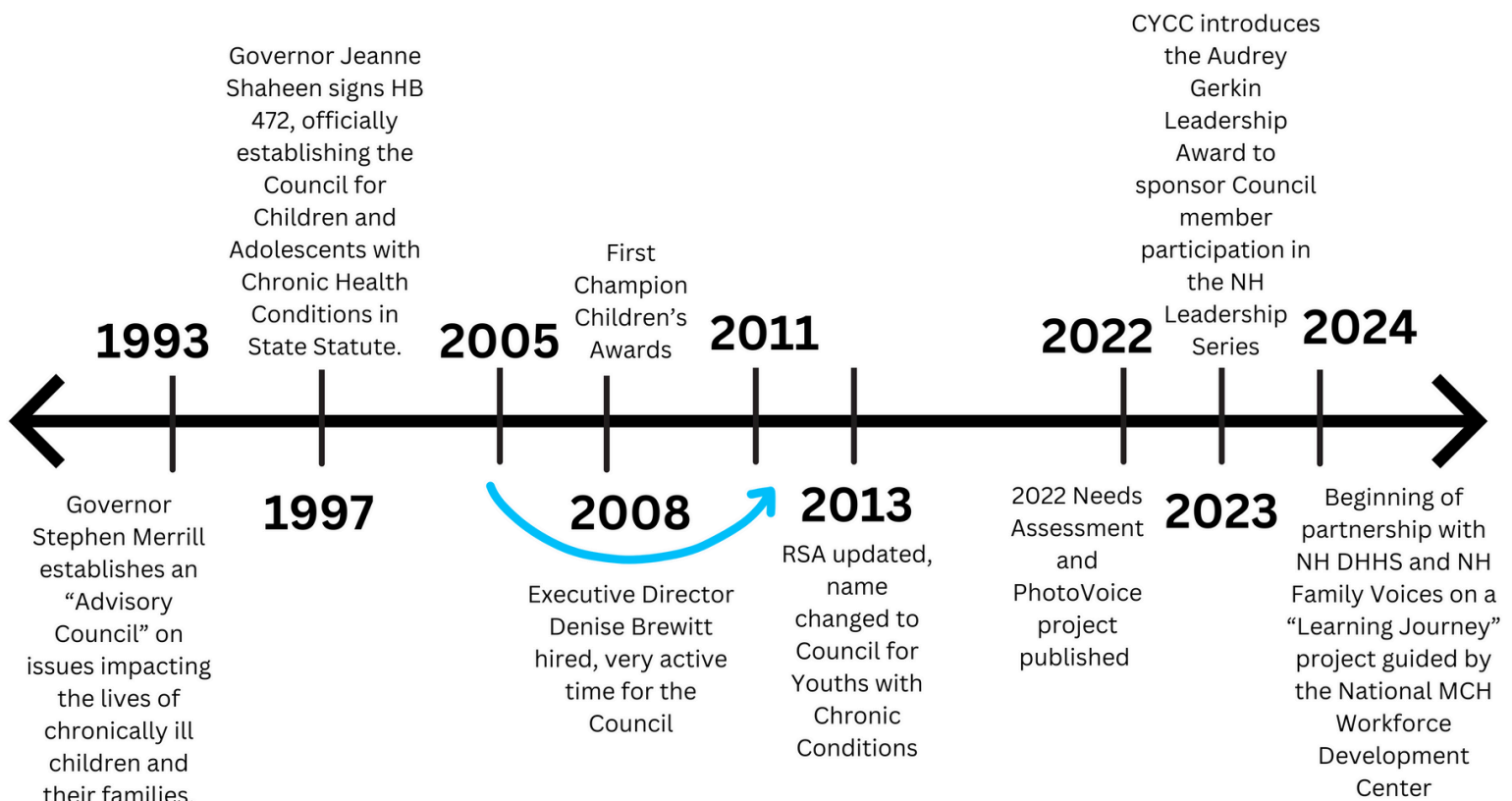
The members of our Council represent family experiences with a wide spectrum of chronic health conditions, including:

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 65,000 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



2024 Council Activities

- **March 2024:** CYCC Director Leah Stagnone traveled to San Diego, CA with team members from the NH Bureau of Family Centered Services and NH Medicaid to begin the National MCH Workforce Development Center’s “Learning Journey.” The team began planning collaborative community engagement initiatives to complement the Bureau’s Needs Assessment.
- **March 2024:** CYCC participated in a Bipartisan Disability Caucus legislative meet and greet, educating legislators about how policy can impact youths with chronic conditions.
- **March 2024:** CYCC Director Leah Stagnone and Treasurer Tim Guidish presented to the NH Leadership Series about the Council and issues impacting youths with chronic conditions.
- **July 2024:** CYCC worked with the Governor’s office on a Childhood Chronic Condition Awareness Week Proclamation.
- **July 2024:** CYCC hosted our annual Kids Chronic Health Awareness Event at the McAuliffe-Shepard Discovery Center in Concord.
- **July 2024:** The Council sponsored GoBabyGo NH cars for adapting and use by children with mobility restrictions.
- **August 2024:** CYCC hosted an information table and connected with community members at the 2024 Family Support Conference in Manchester.
- **August 2024:** The Council presented at the monthly BFCS Care Coordinators meeting.
- **September 2024:** CYCC presented to the Elliot Hospital Pediatrics Department.
- **September 2024:** CYCC launched our first quarterly email newsletter.
- **September 2024:** The Council sponsored participation in the UNH Institute on Disability’s New Hampshire Leadership Series for Council member Jennifer Burbank.
- **September 2024:** In partnership with NH DHHS and New Hampshire Family Voices, CYCC hosted two days of appreciative inquiry sessions, inviting professionals in the system and parents with lived experience to share their insights, feedback, and visions for the future.
- **September 2024:** CYCC partnered with a coalition of New Hampshire disability and chronic health organizations to plan the 2024 Gubernatorial Town Hall on Disability, which was unfortunately canceled due to candidate schedule conflicts.
- **October 2024:** CYCC participated as an exhibitor in the 2024 Rare New England Annual Conference in Farmington, CT, connecting with rare disease patients from across the region.

2024 Meeting Schedule for the Council for Youths with Chronic Conditions

January 17 - 5:30pm

Annual Meeting

Virtual, Zoom

March 20 - 5:30pm

Regular Meeting

Virtual, Zoom

May 15 - 5:30 PM

Regular Meeting

Virtual, Zoom

September 18- 5:30 PM

Regular Meeting

Virtual, Zoom

November 20 - 5:30 PM

Regular Meeting

Virtual, Zoom



Expanding Our Reach

Increased Engagement Online...

In 2024, CYCC was proud to expand our reach in the community both online and in-person.

We built an email list to share updates with the community and launched a quarterly newsletter that quickly collected over 120 highly-engaged subscribers, with open rates averaging over 50%.

CYCC became more active on our existing Facebook and X/Twitter accounts and launched our presence on both Instagram and LinkedIn.

...& In-Person

CYCC interacted with the community at events including the: 2024 Family Support Conference, 2024 Rare New England Annual Conference, 2024 Bipartisan Disability Caucus Legislative Luncheon, and a GoBabyGo workshop where New Hampshire high school students and teachers adapted battery-powered rideable cars for kids with disabilities. This presence in the community allowed us to make new connections and grow out email list!



Summer 2024 Wrap-Up from NH CYCC

Dear friends,

CYCC has had a busy summer, and we're partnering on some exciting events this fall! We are glad to share our first quarterly newsletter with you, covering some of our updates. Thank you for reading!

Have questions or want to get in touch? You can reach out to us at info@nhcycc.org.

Meet Our 2024 Champion Award Recipients!

In July, we celebrated four amazing 2024 Champion Award recipients at our annual Kids Chronic Health Awareness Event. Each year at this event, we honor youths with chronic conditions who have shown extraordinary leadership in and/or commitment to their school and community with Champion Awards. We are excited to share with you about the remarkable individuals whose leadership, advocacy, and community involvement we recognized this year.

[Read About Our Recipients](#)



CYCC's Annual Kids Chronic Health Awareness Event

We had a wonderful time at the 2024 Kids Chronic Health Awareness Event, and it was our best-attended year so far! Thanks to everyone who helped make this a wonderful evening! Some highlights from this year's event were:

- Princess, Spiderman, and astronaut guests

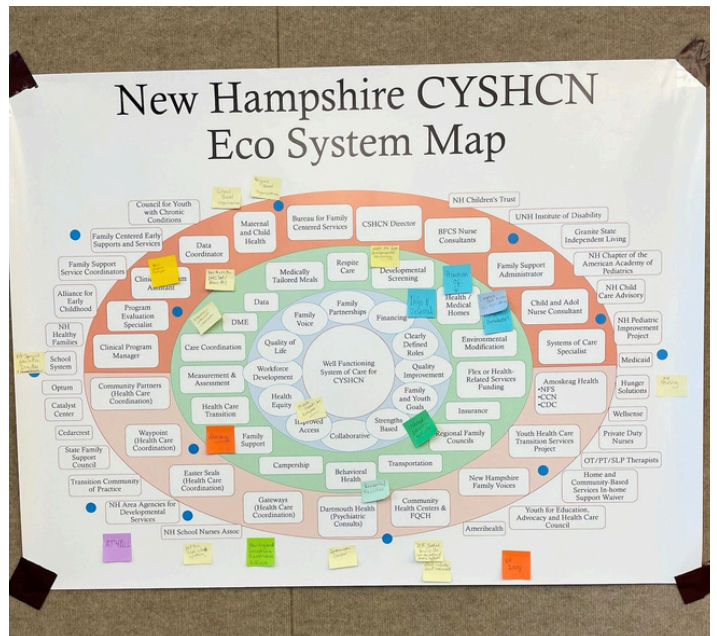
MCH Workforce Development Center Learning Journey



In March of 2024, Council Director Leah Stagnone travelled with a team from the New Hampshire Department of Health and Human Services to San Diego, California for a week of learning and workshops with the National Maternal Child Health Workforce Development Center 2024 Training Institute. The MCH Workforce Development Center helps Title V leaders and partners tackle complex challenges in their state through training, collaborative learning, coaching, and consultation.

During this immersive training institute and in the months that followed, the New Hampshire team collaborated to examine the systems that impact children with chronic health conditions and their families, identifying opportunities for systems change and family engagement.

The team left the Training Institute with plans to connect with additional partners and work together toward a shared goal of engaging families and professionals in innovative ways to envision the future of New Hampshire's system of services.



MCH Workforce Development Center Learning Journey



By September, these efforts culminated in a groundbreaking two-day event hosted by the New Hampshire Council for Youths with Chronic Conditions, New Hampshire Family Voices, and the Department of Health and Human Services. This “learning journey” brought together parents, young adults, care providers, nonprofits, and public servants to collaboratively reimagine New Hampshire’s system of care for children with chronic conditions.

The event included participation from nonprofits and Granite Staters with lived experience, in addition to representation from across New Hampshire’s Department of Health and Human Services, including the Maternal Child Health Section, the Bureau of Family Centered Services, and New Hampshire Medicaid. On the second day of workshops, 21-year-old Justin Bonny, son of CYCC Vice Chair Kristin Bonny, delivered remarks to the group about his experience living with chronic conditions as a young person and what a well-functioning system of care would look like for him.

These two days of workshops followed the model of *appreciative inquiry*. Participants engaged in systems mapping exercises, explored what is currently working well in New Hampshire’s systems, built a shared vision for future transformation, and identified leverage points where change is possible through ongoing collaborative work.

CYCC Celebration Event



The Council held our 2024 Annual Kids Chronic Health Awareness Event and Community Celebration at the McAuliffe-Shepard Discovery Center in Concord, NH on Thursday, July 11th. We honored four Champion Award winners who demonstrate compassion and leadership within their communities and announced Council member Jennifer Burbank as the recipient of the 2024 Audrey Gerkin Leadership Award.

A Proclamation from Governor Sununu’s office was announced, establishing July 7th - 13th as Childhood Chronic Condition Awareness Week, and we read letters from Senators Hassan and Shaheen, who sent their well-wishes.

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
- Spiderman, princesses, and an astronaut live in-person
- Swag bags for youths attending
- Family-friendly door prize raffles



2024 Champion Awards

Champion Awards are given to youths (under age 21) with chronic conditions who have shown extraordinary leadership in and/or commitment to their school and community. Meet our 2024 award recipients!



**Bodhi
Bhattarai**

Before he'd even turned 10 years old, Champion Award recipient Bodhi Bhattarai of Concord testified in front of both the Concord City Council and the New Hampshire State Legislature about the need to make playgrounds more accessible for everyone with varying abilities. He has also played a significant role in the development of accessible walking trails with the Audubon Society in Concord by testing them out and providing his valuable feedback.

Bodhi was nominated by Kathy Bates who recently interviewed him for her blog, From Where I Sit. Kathy wrote about Bodhi, "Most notably, what makes Bodhi unique is that he is already establishing his reputation as a budding young advocate... My conversations with him give me hope for the future of advocacy and the disability rights movement."



**Juan
Rubio-Colon**

Champion Award recipient Juan Rubio-Colon of Meredith is a unified athlete and a leader within his community. He is described as a "shining light in his school community" who looks out for his classmates and checks in with them, as well as "an integral member" of his Life skills Program at Interlakes High School. Juan was recently recognized as Laker of the Month at his high school and is a Class of 2024 graduate. Congratulations, Juan! Thank you for being a leader and role model.

2024 Champion Awards



**Ava
Gregory**

Champion Award recipient Ava Gregory of Keene was nominated by someone connected to the REACH program at the NH Dance Institute, where she danced with 30 other dancers who have various chronic conditions and abilities. She is described as a “role model and leader” to other kids with chronic conditions:

“Back stage and during rehearsals Ava was very caring to all the other dancers. She helped to tie shoes and fix costumes. She spoke with dancers to calm their nerves before going on stage. She played games to pass the time. When one dance took a wrong turn backstage she stayed with that dancer until an adult came to help. Ava made a connection with every dancer on the team and made sure everyone was happy and included.”



**Hannah
Vigeant**

Champion Award recipient Hannah Vigeant of Merrimack has been advocating and volunteering with the Cystic Fibrosis Foundation for most of her life, including 3 years as a Teen Advocate during virtual Teen Advocacy Day with representatives in Washington, D.C. and 2 years as a Great Strides Ambassador. She has helped her family raise just over \$125,000 for the CF Foundation within her lifetime. Additionally, Hannah became a Make-A-Wish Ambassador at 7 years old and has been active ever since, giving speeches to crowds from 10 to 400 people.

Hannah has been involved in her local community as a cheerleader, volunteer, and cheer coach. She is a recent high school graduate heading off to the University of Rhode Island, where she will major in English and Communications.

Looking forward: Anticipated 2025 Activities

- In early 2025, 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.
- In February, the Council will present to the New Hampshire Leadership Series Class of 2025.
- The Council looks forward to hosting our Annual Kids Chronic Health Awareness Event and recognizing young leaders with Champion Awards in the summer of 2025.
- CYCC will continue working to grow our Council, with a focus on appointing a new Youth Member, seeking representation from the New Hampshire's North Country, and establishing representatives from additional professional and community organizations.
- CYCC will continue to conduct outreach to families and stakeholders by presenting to community groups and hosting information tables at chronic health and disability-related conferences and events.
- The Council plans to develop informational resources and webinars for New Hampshire families on topics relevant to youths with chronic conditions.
- CYCC will fundraise to revive an important past initiative: Providing microgrants to families of youths with chronic health conditions who need support with costs related to chronic conditions that are not covered by insurance or other programs.
- The Council will continue to increase our online presence through social media engagement, growing our email list, and creating new blog content for our website that can serve as resources or inspiration for New Hampshire families.
- CYCC will seek out opportunities to develop connections with New Hampshire schools and deliver presentations to school personnel when appropriate.
- The Council looks forward to further collaboration with the Bureau of Family Centered Services, New Hampshire Family Voices, and the National MCH Workforce Development Center, as we build upon the work of our "Learning Journey" project and establish next steps.



Celebrating Our Community



Adapting Outdoors: Bodhi Bhattarai interviewed by the Concord Monitor

In November, the Concord Monitor highlighted accessible outdoor spaces and ongoing efforts by Granite Staters of all ages to make outdoor recreation more inclusive. We were especially glad to see 2024 CYCC Champion Award Recipient Bodhi's Bhattarai's perspective shared in the article. "People underestimate kids with disabilities, but we have creative brains so we can find good solutions," Bodhi said. We continue to be impressed by Bodhi's advocacy and insights!



Saint Anselm Football Signs Tyler Mortimer Through Team IMPACT

Tyler Mortimer, son of Council Secretary Karin Mortimer, was signed to the Saint Anselm College Football team in August through Team IMPACT. Team IMPACT, a national non-profit organization, facilitates a unique multiyear program that matches children facing serious illness and disability with college athletic teams across the country. Based on a clinical model, Team IMPACT guides a symbiotic relationship between teams and children focused on socialization, empowerment, and resilience.