



New
Hampshire
Council for
Youths
with
Chronic
Conditions
(CYCC)

2021 ANNUAL REPORT



CHAIRPERSON'S STATEMENT

Dear Family and Friends of CYCC,

January 7, 2022

As we look back on the year of 2021, we do so with a perspective that is quite different than many other years. We spent 2020 adapting to seemingly endless changes. We as a council not only, carried out our mission and commitment to those caring for children with chronic illness, but focused on reaching out to them and hearing their needs. As we look at 2021, we are able to identify as a council, and community of families, as resilient and adaptable with the ability to thrive in a myriad of situations.

Throughout this past year we have increased our membership, our stakeholder affiliations and collaboration with other organizations to identify and create a community voice across the many issues important to the families we represent. To this, we have begun the process of revamping and publishing a website that will be more accessible, will increase our social media presence, and will allow for donations to be accepted.

We are also pleased to announce our new Council Administrator, Audrey Gerkin. Audrey has served on the CYCC for many years and most recently as Chairperson. Audrey's education, professional experience, as well as lived experience raising a child with a chronic condition, brings a wealth of knowledge and expertise that is wonderfully suited to her success in this position.

Our annual Champion Children's Luncheon was not a viable option this year, yet we were able to maintain the intent and create a new opportunity to celebrate. This year our Champions were those in the educational setting that were recognized for going above and beyond for our children with chronic health conditions. Our Champions, who work as teachers and school nurses, recognized the uniqueness of our children and were exceptional in addressing their educational needs in a variety of settings during an unprecedented global pandemic. Videos were submitted to nominate individuals showing how creative and committed they are to supporting our children.

This year one of our most exciting accomplishments was contracting with the Community Health Institute/JSI (CHI/JSI) to create and implement a comprehensive Needs Assessment that will capture the greatest areas of need for children with chronic health conditions and their families throughout New Hampshire. The results of this assessment will be shared with statewide organizations and agencies that serve our community to assist them in identifying the most effective support systems. This includes CHI/JSI rolling out a statewide survey, as well as conducting listening sessions and focus groups to truly understand the successes and challenges faced by youth with chronic health conditions and their families every day.

As we look forward to 2022, we expect many more challenges for the over 64,000 children in New Hampshire with chronic health conditions. The CYCC will continue to represent and assist them through the pandemic and beyond.

Sincerely,

KAREN LIVERNOIS

NH CYCC, Vice Chair/Acting Chair

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 children and youth with chronic conditions have affordable access to care, supportive home and community environments, and that our families have family supportive work environments.

DEFINITION OF CHRONIC HEALTH 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:

CYCC 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 1 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.



Left to Right from top; Sylvia Pelletier, Audrey Gerkin, Representative Betty Gay, Kristin Bonny, Kate Bailey, AnnMarie Van De Water, Joshua Hilliard, Deodonne Bhattarai, Karin Mortimer, Deirdre Dunn Tierney, Karen Livernois, Nicole Parker, Leah Stagnone, Tim Guidish

Council Members

Name	Position	City
Karen Livernois	Acting Chair/Vice Chair	Londonderry
Tim Guidish	Treasurer	Merrimack
Kristin Bonny	Secretary	Barrington
Deodonne Bhattarai	Parent	Concord
Ann Marie Van de Water	Parent	Bow
Regan Lamphier	Parent	Nashua
Karin Mortimer	Parent	Merrimack
Nicole Parker	Parent	Tamworth

NH State Advisors/Representatives/Appointed positions:

DHHS:	Deirdre Dunn
Community Based Agency Director:	TBD
Education Department:	TBD
Insurance Department:	Josh Hilliard
NH House Representative:	Rep Betty Gay
NH Senate:	TBD

Professional/Community Organizations:

Laurie Fleming, NH School Nurse Association
 Sylvia Pelletier, NH Family Voices
 Dr. Harohalli Shashidhar, Eliot Hospital Pediatric GI Specialist
 Kate Bailey, Epilepsy Foundation New England's AmeriCorps Program
 Member with Chronic Condition, TBD
 Parent Appointed by Governor, Karen Livernois
 Youth Member, Leah Stagnone
 Council Administrator: Audrey Gerkin

HISTORY



The Council for Youths with Chronic Conditions (CYCC) dates back to 1993, when it was known as the Council for Children and Adolescents with Chronic Health Conditions (CCACHC). Governor Stephen Merrill established the CCACHC by Executive Order to focus on issues that impact the lives of chronically ill children and their families. The signing of HB472 by Governor Jeanne Shaheen in July 1997, officially established the Council within the state statutes. Today, there are over 64,000 youth in New Hampshire that are affected by chronic health conditions that the Council keeps in mind while educating and informing the public of their needs.

2021 COUNCIL ACTIVITIES

2021 Meeting Schedule for the Council for Youth with Chronic Conditions

February 3 - 5:30pm
Annual Meeting
Virtual, Zoom

March 24 - 5:30pm
Regular Meeting
Virtual, Zoom

May 5 - 5:30pm
Regular Meeting
Virtual, Zoom

June 9 - 5:30pm
Regular Meeting
Virtual, Zoom

August 4 - 5:30pm
Regular Meeting
Virtual, Zoom

October 6 - 5:30pm
Regular Meeting
Virtual, Zoom

December 1 - 5:30pm
Regular Meeting
Virtual, Zoom

- **2021 and ongoing:** Representation in Title V redesign stakeholder meetings.
- **2021 and ongoing:** Comprehensive Needs Assessment started a year long in depth collection of quantitative and qualitative data looking inside the needs of New Hampshire families caring for children with chronic health needs, which will inform and include recommendations for future efforts by the Council.
 - **May - August 2021:** Request for proposals developed and circulated.
 - **October 2021:** Contract signed with Community Health Institute /JSI Research & Training Institute.
- **September 2021 and ongoing:** Request for proposals developed and circulated to start the website redesign, including universal accessibility, of CYCC website in the coming 2022 year. FirstTracks Marketing was approved by the Council.
- **January 2021:** CYCC council members met with NH's Chief Medical Officer, Dr. Jonathan Ballard and Director of Division of Long Term Supports and Services, Deb Scheetz, to discuss COVID-19 Vaccine distribution phases and inform DHHS of the complex challenges faced by high-risk families.
- **January 27, 2021:** CYCC drafted and submitted a statement to DHHS clarifying vaccine eligibility for certain categories of caregivers.
- **December 2021:** Linda Bimbo, Project Director at the Institute on Disability at UNH presented and discussed findings of the Vaccine Rollout review with the Council.
- **July 2021:** Champion Awards given to teachers and nurses who went above and beyond to service our children during the pandemic. Thank you to Kate Sisneroz, Nicole Gutmann, Geoff Taylor, Dan Provost, and Laurie Fleming. An article was published in the Portsmouth Herald available at www.Seacoastonline.com.
- **April 2021:** The NH Executive Council approved Governor's Sununu's appointment of Karen Livernois as our CYCC gubernatorial appointee member per our bylaws.
- **March 2021:** Former Council Chair and current Council Administrator, Audrey Gerkin, presented at the Institute on Disability's Advanced Leadership Series session on Health Inequity. Audrey spoke about Council priority issues including New Hampshire's private duty nursing shortage.

2021 Champion

KATE SISNEROZ **MONARCH SCHOOL OF NEW ENGLAND**



Kate Sisneroz

The Director of Special Education, Kate Sisneroz, was nominated by her colleagues. She interacts with each student daily at the school and strongly advocates for all of them. Because she has taken the time to get to know her students, she knows how to motivate each one of them. The Monarch School of New England is a private non-profit school, which gives Kate, the opportunity to work with 30 different school districts in the New England area. During the COVID-19 Pandemic, which forced schools to go remote, Kate worked above and beyond to ensure each of her students had what they needed for continued success even though switching to learning at home via virtual school.

NICOLE GUTMANN **MANCHESTER SCHOOL DISTRICT**



Left to right; Nicole Gutmann, Alex and Maria Sieper

A parent watched her son thrive at home during remote school at the direction of his special education teacher, Nicole. She adapted quickly to teaching through a screen and used out of the box thinking to create individually customized materials for each student.

Nicole created tactile story boxes for a child with a visual impairment to make sure he could follow along during virtual learning. She also developed a life skills program for students to continue working on becoming more independent even during virtual learning. We are grateful for Nicole supporting CYCC families last year and are so happy to bestow this award upon her.

Awards

COACH GEOFF TAYLOR & DAN PROVOST EXETER HIGH SCHOOL



Left to right; Dan Provost, Audrey Gerkin, Bayleigh, Pam Becker, Geoff Taylor

These two teachers co-teach a history and English class, called 'American Studies', at Exeter High School. They work hard to meet students where they are at and assist them to meet their fullest potential. One student, Bayleigh, was thankful they encouraged her to find her voice. Their support created an environment during a very difficult pandemic year, which gave Bayleigh a chance to excel academically, despite her high risk health status. Her support accumulated with her ability to write a courageous essay about her American Dream. She shared it with us in her video nomination submission.

LAURIE FLEMING SCHOOL NURSE HONORARY AWARD



Laurie Fleming

Laurie Fleming is a long time member of the NH Council for Youth with Chronic Conditions. She works as a nurse at Hood Elementary School in Derry, as well as sits on the board of the NH School Nurses' Association and as a state representative on the board of the National Association of School Nurses. Laurie provided healthcare and education to her community's students and families during the pandemic, despite enormous pressure and lack of resources. She assisted in organizing the CYCC Champion Awards and our members decided to surprise her with an Honorary Award for her continued selfless work, especially with high risk students with chronic health conditions.



Council for Youth with Chronic Conditions
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