NH Council for Youths With Chronic Conditions

Annual Report 2018-2019

Preface

This annual report is compiled in compliance with RSA 126-I: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 advocate and collaborated to improve the capacities of communities to respond to the needs of families with children and youths with chronic health conditions.

Submitted by:

Audrey Gerkin, Chair

Laurie Fleming, Secretary

Pamela Becker, Council Administrator

January 2019

Dear Family and Friends of CYCC,

Sitting at my computer reflecting on this past year, I am currently excited at the potential and possibilities our council holds for the future. I want to thank past the Director and Chair for their work completed supporting our council and moving it forward, as well as other members who have come to the end of their membership terms. Our new Council Administrator Pamela Becker came on board in August after a lengthy interview process and we quickly regrouped after a year of transition. We've recruited new members and have new representation from the NH state government. We look forward to focusing on families and children who experience chronic health conditions by educating the public, collaborating with state and local organizations and improving community support. We held our Champion Children's Luncheon in November 2018, to recognize the strength and resilience children face with chronic health needs, while at the same time excelling in life and in their communities. We will continue this tradition in May 2020. We look forward to strengthening our current partners and making new ones. We'll be holding a retreat in January for members to focus on our priorities and goals in supporting the children and families that we hold so dear.

Sincerely,

Audrey Gerkin

Chair 2019

Who are we?

The Council for Children and Youths with Chronic Conditions is a parent-focused state council committed to be a voice for families of children with chronic health conditions. We educate and inform policy-makers and stakeholders of the unique challenges and opportunities to expand access to affordable; quality health care; foster supportive work environments; support community-based services and 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, supportive home and community environments, and that our families have family-supportive work environments.

Who are the children and youths with chronic health conditions?

Children and youths with chronic health conditions include those with:

- ⇒ Biologically based condition
- ⇒ Lasting an extended period (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 that typically required by well child and acute illness visits that is not primarily defined as a mental illness or other emotional disability (RSA 171-A, RSA 326-C).

Mission

The Council for Youths with Chronic Conditions (CYCC) was 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.

We hope to achieve this mission by:

- Promoting timely, individualized needs assessments of children and adolescents with chronic health conditions and their families in language easily translated into actions.
- Promoting family involvement at al levels of health care planning, policy making advisory and monitoring capabilities.
- Collaborating with the NH Department of Health and Human Services, the NH Department of Education, the NH Department of Insurance as well as other public and private agencies and organizations that serve or enhance the unique needs of children and adolescents with chronic health needs and their families.
- Facilitating family/physician collaboration at all levels of support and service delivery systems.
- Empowering families through educational opportunities and the dissemination of information that is accessible and compassionate.

Board of Directors 2018

Joelle Martin, Milford, Chair
Sarah Aiken, Concord, Vice Chair
Michael Rollo, Rollinsford, Treasurer
Laurie Fleming, Derry, Secretary
Loretta McGrail, Rochester
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Mariellen J. MacKay, Nashua
Christine Santaniello, Department of Health and Human Services
James Fox, Department of Insurance

In accordance with RSA 126-1:1, 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 € 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. The Council is the only statewide organization that has a legislative mandate to focus on the issues affecting children and adolescents with chronic health conditions.

Guiding Principles:

Guiding Principle #1: Collaborate to Ensure Quality, Affordable Health Care

Since one-third of all children with special health care needs rely on Medicaid or the Children's Health Insurance Program (CHIP) for their health care needs, state policies that govern private and public insurance are vitally important to our youth with chronic conditions. The CYCC has long focused on providing insights and information about the benefits of expanding high quality, community-based health care as well as the state's Medicaid Expansion Program or the NH Health Care Protection Plan. We've convened meetings with partner advocates to listen and assist them. We've found that our voice is larger when we join together.

Guiding Principle #2: Foster Supportive Home and Community Environments

One of the goals of the council is to support and showcase local initiatives that provide unique services, programs, and activities to youths with chronic conditions and their families. In the past, we have spotlighted Camp Sno Mo and Zebra Crossings who both run summer camps that serve children with special health care needs. Each year, the council also tries to recognize a small, local non-profit that's making a difference in the lives of NH youth who live with chronic conditions. The Spirit Award's past recipients have included the NH Chapter that supports those with Prader-Willi Syndrome, and NH Cancer Lifeline. Each year, the council also conducts an educational tour that expands our network and knowledge about home and community-based services.

Guiding Principle #3: Foster Family Supportive Work Environments

Balancing work and family is often listed as the most pressing problem for parents of young children. If a child in the family experiences a chronic condition, it becomes exponentially more difficult and for many, nearly impossible. Even though benefits exist for in-home care and support, NH parents continue to find it extremely difficult to find consistency, reliable care due to tight workforce challenges and entry restriction for some professions. Add to that, the financial demands of working less or not at all, and these demands can create havoc in the home. The CYCC is dedicated to fostering family-supportive work environments. In the past, the CYCC has collaborated with several partners to advocate for legislation to create a Family and Medical Leave program in our state.

2018 Council Activities

Annual Tour

Monday April 16, 2018, the Council for Youths with Chronic Conditions hit the road and visited Family First Health and Support Center in Portsmouth and Richie McFarland Child Center in Stratham. We were joined by Health and Human Services Commissioner Jeff Meyers. The take- away information from these tours was—the effectiveness of trauma informed care and early interventions and the convenience and coordination of services. Each year the CYCC takes a field trip to learn fist-hand about services and programs for families with children and chronic conditions.

Resilience Screenings

CYCC sponsored the film *Resilience: The biology of stress and the science of hope* screenings with a focused panel discussion about (ACEs) Adverse Childhood Experiences. These screenings were in Concord, Gorham, and Milford with a combined attendance of 250 people. Centene co-sponsored the events and helped to pay for the related expenses. The goal of these films was to introduce the overwhelming evidence that links early investments that combat the impacts of toxic environments. Some members of the council also held regular meetings with an informal leadership group about implementing ACEs/Trauma informed care in New Hampshire.

Spirit Award

The 2018 Spirit Award was presented with $500 to NH Cancer Lifeline. The Spirit Award is an award given to a small parent-created non-profit group that raises awareness and assists families afflicted with a chronic condition.

Celebrating 25 Years

The Council for Children with Chronic Conditions celebrated our 25th Anniversary in 2018. On May 4, 1993, then Governor Stephen Merrill created this council (State Advisory Council on Children with Chronic Illness and Disability) with Executive Order 93-2. In July 1997, Jeanne Shaheen signed HB 472 which officially established the Council in the state statue. Senator Maggie Hassan served on this council in its beginning stages.

Advocacy

The Council for Children with Chronic Conditions advocated for Spinal Muscular Atrophy (SMA) to be added to the newborn screening panel. The Newborn Screening Advisory Council voted unanimously to add SMA to the panel. This work has been in progress for years and it was difficult to gain ground until this council got involved.

Recommendations

The 2018-2019 Council for Children with Chronic Conditions recommended the following:

Department of Education- Fund the School Nurse Consultant position

Department of Health and Human Services

Collect ACES data

Expand the home visit program

Invest in family resource centers

Recommend using the school immunization report to collect information about the number of children with chronic conditions in New Hampshire.

Champion Children's Awards 2018

The Council for Youths with Chronic Conditions' signature event is the "Champion Children" award luncheon. Children are nominated by school nurses, teachers, guidance counselors, and health and community leaders for this recognition. The 2018 Champion Children's Luncheon was held on November 26, 2018 at the Holiday Inn in Concord. Well Sense Health Plan sponsored the event which gave awards to 16 Champion Children, one Service Champion, and one Community Champion. We were joined by multiple legislators and our own Wonder Woman Destinee DiPrima. We are proud to highlight our award recipients.

Hon. Steve Shurtleff and Destinee DiPrima

Champion Child Nominees

Nominee: Anthony May

I first met Anthony in Kindergarten. Though I had read about his history of Hypoplastic Left Heart Syndrome (HLHS) I was amazed at this young boy who I would never suspect had a physical problem at all. He kept up easily with his classmates and had few nurse visits.

Anthony most always has a big smile on his face which is a bit contagious because you think if he can have a big smile after all he has been through then all of us should be smiling big.

As with other children with this challenge he had undergone 3 palliative heart surgeries by the age of 3. His mother says "I call him my miracle baby because after his surgeries as all kids with HLHS lose weight and have a hard time eating and gaining weight back, Anthony had the doctors stumped. He was gaining weight just like a normal baby and didn't have any of the symptoms he should have had, I had all the doctors sit me down and question me as to what I was doing my routine with Anthony when he was an infant to try to figure out if I was doing something different than other mothers why my child was doing so well he was a medical marvel."

During the 1st and 2nd grade Anthony would come in from recess reporting a headache. I would do the usual check of his pulse oximetry to make sure he was circulating enough oxygen and checking his heart rate and rhythm with my stethoscope. Anthony would occasionally listen too with our double stethoscope. I would remind Anthony to drink a lot of water because of his headache and it is one of the instructions from his parents especially pertaining to recess. Anthony was very cooperative.

Anthony has a busy family life with 3 siblings, his parents and multiple pets, especially dogs. Unfortunately, last year Anthony caught strep throat which was circling around the school more than once. This caused an arrhythmia and Anthony had to be hospitalized. When he returned home his mother nursed him back to his normal state of health. He was out of school for a while and was anxious to get back. When he returned, he still had his winning smile and we were all excited to see him again.

This child does not complain. He is optimistic on a daily basis. He does what all the other students do. If he falls, he gets right back up. His medical problem does not define him and in fact unless a person read his file, they would not know he even had a problem. I have thought of him every year this has come out but finally brought it up and the Principal spoke to his mother who gave her permission.

Anthony is a hero because of the way he lives his life, despite any medical problem he has.

Karen Stafford, RN

Jennie D. Blake School

Nominee: Grace Denney

I wish to nominate one of the students on my caseload, Grace Denney for the Champion Child award from the Council for Youths with Chronic Conditions. Some of the back-ground information can be found in this article from Boston Children's Hospital:

https://thriving.childrenshospital.org/saving-grace/

Grace has a life-threatening peanut allergy so severe that air born particles can cause a trip to the hospital. Grace was home-schooled for a period of time due to her fear of having another reaction and the uncertainty of how an attack could be triggered. She will be entering her sophomore year here at Gilford High School and she has brought so much. She is a top student, a dedicated member of the performing arts department and she brings a maturity that is an inspiration. Grace is an "old soul" who through her own struggles has become a young woman of great empathy and strength. It has not been easy for her by any means. The concern is real every time she enters a classroom: "had someone forgotten in the last class that this has to be a nut free zone" or "will someone I sit with at lunch bring a peanut butter sandwich?" Both of these situations could cause immediate hospitalization. In addition insensitive comments such as "If you ate a peanut would that be like you committing suicide?" have been difficult but have never caused her to lose focus on her goals, retreat in fear or even lose her sense of humor. Invisible illnesses can be so hard on kids because they don't "look sick." We are better off having Grace in our school for her spirit and with her wit, tact and compassion, she is teaching us all a lesson in grace.

Respectfully submitted,

Monica Sawyer

Nominee: Dan Nester

Dan is a bright spot in our school. We all look forward to his daily newspaper delivery, which includes his infectious smile and a chance to see what new handkerchief he has on his neck that day. Despite his health challenges, Dan is enthusiastic and ready to greet each new day - waiting at the door to welcome staff as they enter the building and going full tilt for bowling and skiing field trips. Dan is also currently working in the dining hall at Colby Sawyer College and at his new job at Concord Hospital. He inspires us all with his kindness and joyful attitude.

Nominee: Eyob O'Connor

It gives me great pleasure in introducing Eyob O'Connor to you and the CYCC network. This was Eyob's first summer at Easter Seals' Camp Sno-Mo, not that you would have guessed this by how quickly and effortless Eyob navigated his way around the many program areas here at camp. The property spans 3,600 acres and has all the traditional program areas you would expect to find at a summer camp here in New Hampshire.

Camp Sno-Mo works closely with the Daniel Webster Council (Boy Scouts of America) in offering the experience of a lifetime. With the help of the many program staff here at Hidden Valley, our campers participate and earn merit badges in much the same way as any regular boy scout attending the camp. Our campers get to learn about STEM and Ecology, and how to climb, sail, shoot, and swim, to name but a few of the activities.

Eyob has an infectious smile and a manner about him that is humbling. Every challenge is met with a "yes, I can" attitude, so much so that camp invited Eyob back to camp to become a CIT (counselor in training). This is a voluntary position and one Eyob grabbed with both hands and ran with. Eyob attracted the attention of the Boy Scouts with his positive and upbeat approach to everything and everyone. They even went as far as consulting me regarding the possibility of Eyob becoming a summer staff for the Boy Scouts.

Both Eyob and Camp Sno-Mo appreciated the offer and interest from the Boy Scouts but declined their invitation because if there is any place Eyob would be working, "first and foremost" (his words), it is alongside Camp Sno-Mo staff and campers.

Sincerely,

R.E.Kelly

Nominee: Timmy Dindeen

When I saw that the Council of Youths with Chronic Conditions was seeking nominations for their Children's Champions Awards, I didn't even blink before I thought of our student Timmy Dineen.

Timmy has been a student at South Range Elementary School in Derry since Kindergarten and is currently in 5th grade. He is a good student and is involved in many extracurricular activities including Running club, Champions club, Lego club, Kids Care club, Destination Imagination, Spanish Club and Chorus to name a few. He embodies the qualities of dogged resiliency, cheerful optimism, and determination! He is an absolute pleasure to be around and serves as an example to our school community.

Timmy was born with Arthrogryposis Multiplex Congenita (AMC). This rare congenital disorder is characterized by multiple joint contractures and can include muscle weakness and fibrosis. All of Timmy's extremities are affected. He has undergone more than a dozen surgeries in his life related to this condition. He makes accommodations for himself and is very independent in most tasks! He can walk (and sometimes run) with adaptive braces. Three years ago, he developed hip pain and since then is also being followed for avascular necrosis of his left hip (Perth's disease). Because of this, he uses a wheelchair for any distances in school. He may walk within classroom and for shorter distances. Despite this, Timmy sees no limitations for himself.

As aptly described by our Principal, Matt Olsen, "Tim is a boy who thinks and acts beyond any limitations. He is always happy and maintains such a positive attitude, and he cares about others.

He is the epitome of perseverance and is an inspiration to those who know him."

Our physical education teacher, Jake Filip, also describes him well:

"Tim Dineen is an outstanding student that I have had the pleasure of teaching physical education to for the past 5 years. Over half the time Tim visits me in the gym he is in a wheelchair. He has always had a never give up attitude to go along with the most positive demeanor possible. I often refer to Tim outside of my school job as someone who completely embodies the word perseverance. I have never once heard Tim complain about his position in life and the cards he was dealt. There is never a time where Tim asks me to "take it easy on him" or can we "change it so that I don't have to do that?" kind of a question. He has the biggest heart and refuses to allow himself to feel any different than anyone else. He is a true champion! He embodies this even more by joining the running club the past two years. He competed in a race last year for 4th grade boys that included close to one hundred participants. He was allowed to sit in his wheelchair and push himself around an outdoor football field track while the other boys ran a mile. Tim was able to complete this task alone in less than 14 minutes. He received first place for the wheelchair division! He received thunderous applause from hundreds of parents that witnessed his act of courage and determination. Tim Dineen is my hero!"

Many staff members were clamoring to support Timmy for this recognition. The common theme that consistently shines through is that he is great role model for his peers and always has a smile on his face. Whether participating in extracurricular activities or giving great insight in class discussions, Tim always conquers his work with a positive energy. Tim uses his positive energy and thinking to help other classmates that may be having a hard time. So, for these reasons, and many, many more that are numerous to list, I would like to nominate Timmy for a Champion Children's Award! He is certainly more than deserving and is a shining example to all on what it means to be a champion.

Susan Linehan BSN, RN

School Nurse, South Range Elementary School

Nominee: Sean Corey

Sean Corey is a charming 11-year-old boy with a medical diagnosis of kidney disease. Sean has gone through many medical procedures and has learned to live with and advocate for his medical needs and concerns. At doctor's visits he will engage in a conversation with the doctors about his kidney disease and ask questions. At meetings with school personnel, Sean will also engage in conversation and join in the meeting to tell about things he has overcome as well as advocate for his needs.

He was recently in a play and played the "king!" What an awesome job he did!! Sean is such an engaging, energetic, polite and charming young man! He always has gifts for people when he sees them and greets them with a smile, nice to see you and thank you for coming!

Sean has been a role model for me in showing me how to overcome obstacles in one's life while growing in many ways as a person!! I know he will continue to grow and charm many more people in his lifetime!

Thank you!

Maura Pennisi

Nominee: Maggie Hotz

Maggie lights up the room of whatever setting she's in. When she comes to school on Mondays her friends are jostling one another to be the one who gets to push her wheelchair. Despite her health challenges, Maggie is involved in numerous activities- bowling, skiing, swimming, and horseback riding. She is also now well known and loved in her extended community - working at Colby Sawyer College and attending the local library story hour, where Maggie is a hit with the children. Maggie is always willing to try something new and is beginning a new art class in the community. Her smile and cheerful disposition are examples of the power of positivity for everyone who meets her.

Nominee: Matthew Jacques

I have had the good fortune of being the school nurse at Hampstead Middle School for one full school year. In that time, I have met an amazing young gentleman named Matthew. He was diagnosed at a very young age with Type I diabetes. He has had his share of struggles with the disease throughout his very young life. However, he does not let this define him.

He shows up every day to school ready to learn and of course spend time with his friends. He manages to play hockey throughout the year with a traveling team outside of school all while being on the cross-country team in the fall, skiing in the winter and track in the Spring (sports in school). He has a very loving and supportive family. He will talk about his brothers and sister and his parents on many occasions in my office. You can tell they have a close bond. In my observation, he takes on challenges with a determination to be the best he can be and helping others along the way by being a good example and mentor. He is an active member of the Sunshine Squad (a club which started last year with the purpose of showing kindness to others) that is led by one of our school counselors. She has said that he takes it upon himself to help lead the group in discussion about being respectful of others and keeps other students in check when they are not. He is well mannered, polite, fair and courteous. He does not complain or let his disease slow him down. He is an A/B student and works very hard to limit his trips to the health office. One story he told me about was that he was outside, and it was cold, but his brother was not letting him back in the house and said to him, “it’s all a state of mind”. These words left an impression on him because I believe this is how he lives his life.

This is a poem that I have found that is how I see Matthew Jacques and the way he lives his life.

It's All in the State of Mind by Walter D. Wintle

If you think you are beaten, you are,
If you think that you dare not, you don't,
If you'd like to win, but you think you can't,
It's almost certain you won't.
If you think you'll lose, you've lost,
For out in the world you'll find
Success begins with a fellow's will—

It's all in the state of mind.
Full many a race is lost ere even a step is run,
And many a coward falls ere even his work's begun,
Think big, and your deeds will grow;
Think small, and you'll fall behind;
Think that you can, and you will—
It's all in the state of mind.

If you think you are outclassed, you are;
You've got to think high to rise;
You've got to be sure of yourself before You ever can win a prize,
Life's battles don't always go to the stronger or faster man;
But soon or later the man who wins Is the man who thinks he can.

Julie Nielson

School nurse, Hampstead

Nominee: Catalina Alzate

Catalina is a nine-year-old girl who was born with spina-bifida that requires her to use a wheelchair, or her braces and crutches to get around. This past summer she developed epilepsy. Despite this, Catalina possesses one of the sunniest dispositions of any child I have met in my 21 years as a school nurse. She is always cheerful and has a smile and kind word for everyone she meets.

Catalina is also blessed with compassion for our students who have mental or physical differences, that most of the other children tend to avoid. She has a lovely way of being sweet and kind to absolutely everyone. I've watched her with some of our autistic children who have been anxious waiting for the bus to arrive at the end of the day, and Catalina seems intuitively know how to speak to them to help calm their fears.

I think it would mean the world to Catalina and her mom if she was to be recognized for her resiliency and optimism.

Janet Bross, RN

Jewett Street School Nurse

Nominee: Kendal Cote

Hi! I would like to nominate Kendal Cote, age 11. I have known Kendal for a couple years but not until she arrived at the middle school did I realize what a resilient and amazing girl she is.

Kendal was diagnosed with Type 1 diabetes at the age of 8, in the summer before she started 4th grade. The date was July 22, 2016 to be exact. I tell you this because she tells everyone the date. It was the day that her life changed forever and she and her family honor that day by calling the number 22 her "lucky number".

Kendal amazes me every day. She manages her diabetes independently with minimal staff guidance, makes good choices about what she eats, and answers her classmate's questions with confidence and ease. She does all her testing in class, so she doesn't miss anything. Kendal hates to be out of class and hates to miss school. Even when she has doctors' appointments, she comes to school before and after, if possible.

Kendal plays 3 sports, soccer, basketball, and her ultimate favorite, softball. (Her jersey number is 22 of course!). She doesn't let her disease slow her down. Just like school, she doesn't want to miss anything, and it is very rare that she misses a practice or a game. She is a team player all around. Kendal arrives at school every day with a smile on her face. She has had some tough times with her disease, but she always has a positive attitude. Emotionally she bounces back quickly and moves on. I look forward to seeing her every morning. She is a joy to care for.

Kendal's parents and family are wonderful and very supportive. She is who she is because of them. They are involved in the JDRF and raise money for the walk in Manchester every year.

Kendal is a Champion in my eyes! She is an inspiration to the staff and her classmates!

Robyn Lantz RN BSN

School Nurse

Charlestown Middle School, SAU 60

Nominee: Nathan Ladd

Nathan epitomizes the qualities of resilience and positivity; living with Cystic Fibrosis has not dampened his enthusiasm, good humor, and sunny disposition. Nathan has a smile for everyone and is quick to notice when someone else may need a pat on the arm or a little affirmation. He is empathetic to peers and faces challenges with a smile and willingness to give his best.

Nathan is a good self-advocate- he seeks my assistance when he needs it, tries his best to follow my requests, and is always gracious, polite, and appreciative.

I can't say enough good things about this wonderful child, and I believe he deserves recognition!

Karen E. Utgard, MSEd, BSN, RN

School Nurse

New Franklin Elementary School

Nominee: Kelly Frasca

I had the pleasure of meeting Kelly during the summer of 2015. She was a young, wide eyed, upcoming freshman who had just moved to Amherst. Within minutes, I knew she was going to take Souhegan High School by storm. Packaged in a tiny frame, her tenacity, kindness, intelligence and passion for learning was evident. What I didn't know until later, was what a fighter she has been since birth!

Kelly was born at 35 weeks, just 3 lbs. 6 oz at birth and spent the first 4 weeks in the SNHMC NICU. Her umbilical cord had only 2 blood vessels in it, when there should have been 3, so she didn't get enough nutrients, thus her low body weight. She was sent home from the hospital at 3 lbs 11 ozs. The Neonatal doctor commented she was the smallest baby he had ever sent home but assured her parents he was confident with the decision because she was as strong as an ox. Health complications continued through her life. Kelly displayed multiple bronchial infections as well as bilateral kidney reflux and failure to thrive. She had many, many visits to the ER for breathing issues and high fevers. She was always fully up to date on vaccines, nevertheless contracted Pertussis in the summer of 2007, missing about 4 months of first grade. The Pertussis was the precursor to asthma, which could never quite be kept under control. Between 2008 and 2009 she contracted pneumonia 11 times despite having been vaccinated for a number of different strains. Needless to say, she missed large amounts of school—in 3rd grade alone, she missed 65 days. Knowing the student, I know, school is one of her favorite places on earth, and even at young age, I am certain she was upset that she was not in the classroom with her peers.

The doctors at Boston Children's struggled to determine the causes of her bronchial issues, thinking that possibly the ventilation systems in the schools could be affecting her. She was transferred around in the Nashua school system to see if different buildings might make a difference. Nothing seemed to help. The uncontrolled asthma and high fevers continued, along with trips to the ER that were too numerous to count. In 2010, her primary care physician asked if Kelly's parents, Bev and Bob, would consider getting some second opinions from the doctors at the Children's Center at Mass General Hospital (MGH). It is there that they met Dr. Craig Canapari. He was determined to figure out what the causes of Kelly's multiple medical issues were. After months of blood work, MGH determined that despite the regular vaccinations, Kelly's body did not build up immunity to the Pertussis or the Pneumonia vaccines. Dr. Canapari put her on prophylactic antibiotic so that she could attend school on a regular basis. She continued this regimen for 4 years.

In 2015, Kelly and her family moved from Nashua to Amherst. She had pneumonia that fall and ended up missing a few weeks of school. This was incredibly difficult for Kelly, as she is not just your regular old kid in high school, she is a driven, motivated learner. By late in the fall of 2015, the doctors finally determined that Kelly had an immune system deficiency. The treatment is not easy and includes biweekly infusions of immunoglobulin that she administers to herself subcutaneously. It takes about 3 hours each time she does it. Needless to say, it is another indicator of just how strong this young lady is.

Kelly is now a senior. She is a strong student who takes the most rigorous courses and maintains a 3.6 GPA, taking on the Honor's challenges offered and is enrolled in AP courses. Aside from her impressive academic profile, Kelly has worked to remain a well-rounded student. She is an active member of Ethics Forum, Theatre, A Capella, is a Track and Field Varsity team member and the Vice President of the Thespian Honor Society. Kelly is also a HYPE Facilitator at the student led conference held at UNH and she is one of our suicide prevention student trainers. Did I mention she also has a part time job? This is an impressive resume for any student, let alone someone who has beautifully navigated the health challenges she has faced throughout her life.

I am proud to have been a small part of Kelly's high school career and know she will continue to develop into an incredible young person ready to take on any challenge!!

Sheelu Joshi Flegal, LICSW

School Social Worker

Souhegan High School

Nominee: Lauren Small

I am so pleased and excited to nominate a student for a Champion Youth Award from the Council for Youths with Chronic Conditions. The student is Lauren Small, Grade 12, at Milford High School. She has lived with a disability since her young years from a history of cerebral (brain) tumor and removal. She is always smiling, takes initiative in class and has a very strong work ethic. Lauren is a challenged reader, but" reads all her books to the end", according to her book club associates. She shows concern for others, she is self-directed and always respectful. This is her first year that she doesn't have a 1:1 paraprofessional working directly with her.   She is active in "Best Buddies" and has become much more social and "open" lately according to the MHS Librarian who has been working with Lauren for three years. I want to nominate this amazing young woman for a Champion Award because she is a CHAMPION in my eyes and I always love seeing her in the halls and in the Health Office. Sometimes, I must take a second look to be sure it is her because Lauren does like to change her lovely hair color at times to keep us all guessing and to have FUN!

Mary Arrowsmith, RN, BSN

Milford High School Nurse

Lauren and Joelle Martin, Chair

Nominee: Autumn Farnum

When I greet the campers and their families to Camp Spinnaker (a 6-day residential camp for children who have asthma), I get to observe all of the emotions that are part of arrival. Most campers, regardless of how seasoned, are a combination of excitement, curiosity, and nerves. This summer, my attention was caught by Autumn, who strolled up to the registration desk, relaxed, confident, and full of smiles. She was completely at ease. As cabins begin their opening activities, I watched Autumn befriending and reassuring new campers as she bounced into each challenge. She used her positive energy and prior experience to assist the new campers as well as the counselors. As the week progressed, I watched Autumn balance seeking her personal challenges with supporting others to achieve as well as sharing her story with listening to others.

As I think back to Autumn's first time at Camp Spinnaker, I am completely amazed at who this child has become. Over the past 2 years, she has learned so much more than how to better manage her asthma. The independence and confidence gained from the first stay at Camp Spinnaker seemed to allow Autumn the opportunity to explore her own abilities and become comfortable in her own skin. This inner peace has transformed Autumn into a person who can think beyond herself, supporting others and being sensitive to their needs. It has also given her the gift of resiliency enabling her to try, try again, and try it a different way. She has become a leader not only in the Zebra Crossings community, but her school community as well where she has received several awards. Autumn truly is a person who adds value to her communities and serves as a role model for what is possible.

Astrid Wielens

Executive Director, Zebra Crossings

Hon. Steve Shurtleff, Autumn, and Wonder Woman (aka Destinee Diprima)

Nominee: Tyler McGibbon

I would like to nominate Tyler McGibbon for a Champion Youth Award. Tyler is a ray of sunshine in our school. He comes in to school happy and ready to go. He is friendly and very concerned about everyone he encounters. Tyler has a Chromosome 13 Deletion, asthma, bilateral hearing loss, a severe peanut and pecan allergy, Migraines, and Hydrocephalus. Despite having these ongoing disabilities and chronic diseases, Tyler always tries his hardest. At Gilbert H. Hood, he is known by students and staff as the mayor of the building. He loves the police and fire departments and is a joy to everyone who knows him.

Laurie Fleming, RN, MPH, NCSN

School Nurse

Gilbert H. Hood Middle School

Derry, NH

2018 Community Champion Award

Lt. Steve Tenney

Lieutenant Steve Tenney is a U.S. Army veteran and 18-year member of the Keene Police Department and a coach for the Monadnock Regional High middle school football team. Steve saw a GoFundMe page about a 4-month-old little girl named Sloan who was deteriorating rapidly due to a liver disease called biliary atresia. This disease made Sloan's liver to fail and her only hope was a liver transplant. Lieutenant Tenney saw that Sloan was fading fast and decided to get tested to see if he was a match. Lt. Tenney was a match. He said, "Fortunately, here, I was in a good position. My wife and I talked, and it was really a no-brainer- if you can help a 4-month-old and potential safe her life, it's something you're going to do." Lt. Tenney reported to Lahey clinic where he underwent numerous procedures such as a CT scan, MRI, and liver biopsy. He estimates that doctors took hundreds of vials of blood. They took three-dimensional images of his liver, as part of the transplant surgery involved collaborating with a lab in Germany. Tenney's vessels and veins had to be compatible with Sloan's.

On September 8th, Lt. Tenney gave Sloan about 20% of his liver to Sloan. Both surgeries were successful. Her liver will grow as she grows, and the lost section of Tenney's liver will regenerate. Sloan's family is so thankful that Lt. Tenney reached out when all of this started saying "it reminds us that there are great people in the world." Tenney says he wouldn't change a thing. "Having been through it, it's something I would tell people to do if they're in that position. I have no regrets. For what you give, it's a very rewarding process in what you get back."

2018 Service Champion Award

NH Bayada Pediatrics

I would like to nominate Bayada Nursing Agency, the Manchester Pediatric Home Health Nursing dept.   They opened their doors officially in September 2017 because of the increased reimbursement rate, which allowed for a higher wage for in home nurses. Since then they have been able to provide much needed services to families caring for children with chronic health conditions and complex medical needs in NH, where there were large gaps in service beforehand. I understand that families that were struggling to receive approved services were contacting the Disabilities Rights Center because needs were not being met. The DRC has found Bayada to be a home health company that is raising the bar for standards of care and provision of services in NH. Bayada also provides much needed training right in their office with a pediatric simulation lab for nurses, so they know how to appropriately care for the children they work for, including trachs, ventilators, and G and J tubes. No other pediatric home health agency in the state provides this type of specific training.

As a family who personally receives services from this company for our daughter, we can attest to that. We are treated with respect and compassion. The agency works very hard to fill all the hours needed and they do not stop until the shifts are filled. The nurses are treated with respect and rewarded for their hard work. The company strives for a positive culture, which makes all the difference when families are living through medical crises. For example, my daughter spent most of September in the hospital, and our main in-home nurse quit during this time. Bayada was able to refill the position before we returned home from the hospital. Previously, when this occurred during another hospitalization with another company, our main nurse quit and it took 3 months before the shift was filled, and our daughter staying at a pediatric facility for 2 months for medical care. Bayada provides a tremendous amount of stability for our home and ultimately saves the state countless dollars of unnecessary spending in medical institutions.

http://blog.bayada.com/bayada-news-blog/bayada-expands-services-in-new-hampshire

https://www.bayada.com/offices/nh/manchester/33-lowell-street/pediatrics

Cathy Slack is the Director of the Manchester Pediatric Home Health agency.

603-413-7100

cslack@bayada.com

Thank you,

Audrey Gerkin

Mom of Lexi Gerkin

2019 Council Activities

2019 Board of Directors

Audrey Gerkin (Chair)
Laurie Fleming (Secretary)
Deodonne Bhattarai
Destinee DiPrima
Tim Guidish
Kristin Bonny
Karen Livernois
Ann Marie Van De Water
Latha Magipudi (NH House representative)
Heidi Petzold (Partners in Health Agency representative)
Dee Dunn (DHHS representative)
Pamela Becker (Council Administrator)

The end of 2018 presented challenges for the council due to a change in leadership, and a state decision that the new Council Administrator and the budget should be shared with the Developmental Services Quality Council and the NH Council on Autism Spectrum Disorders. The chairs of the three Councils went through a lengthy hiring process to clearly define what they were looking for in this new leadership position. They developed a new job description that included providing leadership to the Councils and supporting their efforts and would ensure collaboration and unity among the Councils. The Memorandum of Understanding was designed to further the missions of the three Councils and increase communication and cooperation.

In the end, the Councils could not reach a philosophical consensus and the Developmental Services Quality Council and the NH Council on Autism Spectrum Disorders went in a different direction. The new Council Administrator was hired to work with the CYCC.

Even while this process was ongoing the Council was able to progress in some of their focus areas including legislative advocacy, equitable mental health reimbursement rates, Medicaid certification for school nurses and inclusion of Spinal Muscular Atrophy (SMA)in at-birth genetic screening.

We have continued to grow our membership with new parent members and outreach to other agencies that have similar interests with different segments of our population to promote collaboration. We strive to increase our diversity and expand our outlook.

Champion Children Awards

We are currently changing the parameters of the Champion Children's award. It will more fully represent the youths who have overcome adversity and have achieved success despite the challenges of living with chronic health conditions. In order to accomplish these changes we decided to postpone our 2019 ceremony until 2020 so we could put in the time and effort to reorganize the celebration for the children.

We plan to include a Spirit Award for a parent created organization that supports children with chronic health conditions and their families.

Current Priorities:

The Council is focused on continuing to ensure our youth with chronic conditions and their families have affordable access to care, supportive home and community environments, and family-supportive work environments. We continue to strengthen parent voices by improving and developing our partnerships, communication and collaboration, and by focusing efforts on advocacy.

In May, we will celebrate our Champion Children at an awards luncheon in Concord.

The Council is energized by the changes we have experienced and have renewed our commitment to the mission of assessing and improving 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.