

Council for Youths with Chronic Conditions

Annual Meeting

January 19, 2022

Zoom meeting 5:30-7:30pm

Attendance: Audrey Gerkin, Kristin Bonny, Karen Livernois, Deirdre Dunn Tierney, Sylvia Pelletier, Nicole Parker, Joshua Hilliard, Kate Bailey, Laurie Fleming, Tim Guidish, Regan Lamphier, Karin Mortimer, Leah Stagnone.

Invited guests: Jan McGonagle and Carole Smith from the Complex Care Network.

Dr. Jan McGonagle from the Complex Care Network (CCN): Invited to speak about Covid in regards to the CYCC population. She began by sharing who the Complex Care Network is and what they do.

- They conduct consultation and collaboration with families, schools, medical professionals, nurses, social workers, and other community agencies caring for children.
- Consultations are most often used to teach schools, usually per parent request but schools can also initiate a request for consultation.
- The team consists of an educator, developmental pediatrician, a physical therapist, and Carole Smith.
- Most consults are done virtually
- Available to any NH resident with medical complexity. They will follow kids to age 21 and will help with transition beginning at 16.
- It is free.
- Contact Carole Smith at the CCN 603-271-4488 to make a referral. Audrey has a copy of the CCN brochure to share upon request.
- Requested that the CYCC share the CCN's information with families.

Dr. McGonagle also shared about her interest in the research around resiliency and what predicts life satisfaction for people with complex medical conditions? She stressed the importance of promoting resiliency in youth with complex medical conditions.

Dr. McGonagle then began her discussion on Covid. She reviewed recent data on Covid and testing. She discussed the difference between the PCR test and the Antigen test (home test). Important points made were.

- PCR- picks up any piece of virus.
- Antigen test- The whole virus has to be there, not just a piece of the DNA.
 - Positive means positive.
 - If you test negative, 2-3 day window where you could be infectious. Retake the test in 2-3 days and if you are still negative then you are negative.
 - If you test negative and you have symptoms, you got a good wet sample, then you are negative.

Discussion continued around kids with trachs or who need nebulizer treatments during the school day. They are having a hard time returning to school because the trachs and nebulizers can aerosolize the virus.

She discussed mutations, specifically Omicron, and the basics of how the mRNA Vaccines work. Key points made were.

- The vaccine does not prevent you from getting Covid it prevents you from serious illness.
- Those that get serious illness and are vaccinated are immunocompromised.

Dr. McGonagle shared results from the CDC study of 43,000 kids, all hospital admissions less than 18, who were positive with Covid. Key points shared were.

- $\frac{1}{4}$ of the kids studied had underlying disease.
- Disease and risk factors were similar to adults. They were obesity, cardiovascular disease, congenital anomalies of the heart, Type 1 Diabetes, immunosuppression *not malfunction but lack of response*, sickle cell, uncontrolled asthmatics, ex premies due to lung disease issues, neuro developmental disorders with epilepsy, *not stand alone well controlled epilepsy*, and neuro developmental disorders where masking is an issue, or they frequently touch mouth, nose, eyes, or there is decreased lung capacity, or there is an inability to communicate symptoms.
- The mortality rate is low, highest among teens.

Final questions/comments.

- Call the public health department to find out who is treating 12-18 year olds with monoclonal antibody treatments.
- Discussed the stages of Covid and why some begin to feel sick again after they had started to recover.

Council Business

Announcements: Brian Collins is retiring. Deb Guenther at NH Leadership asked for a representative from CYCC to speak at their March Seminar. Anyone interested in presenting to NH Leadership should let Audrey know.

Secretary Report: (Kristin Bonny) Meeting minutes were reviewed prior to the meeting. Kristin made a motion to approve the minutes and Karen seconded. Minutes approved.

Treasurer's Report: (Tim Guidish) Tim reviewed the budget. First payment to JSI has been made. First tracks sent the first invoice for the website rebuild. Karin made a motion to accept the budget report, Regan seconded. All were in favor.

- a. ABLE NH requested CYCC to be a sponsor for their Soaring for the Stars fundraiser. For \$250.00 our name would be included in their literature and on their social media and website. The CYCC has done this in the past. Concerns were raised regarding the fact that ABLE is an advocacy group and we are not allowed to use state funds for advocacy. It was mentioned that we could lose funding. Karen made a motion to not sponsor ABLE, Tim seconded the motion. All were in favor.

- b. Financial Disclosure form: All members of the CYCC Board need to fill out a financial disclosure form and send it to the state. Audrey emailed us the link to fill it out online or print it and mail it. Going forward it will be included in new member packets.

Membership:

Executive Council Elections were held. Audrey shared term limits of those that were nominated. A suggestion for next year is voting by poll.

Nominations:

Karen Livernois for Chair
Deodonne Bhattarai for Vice Chair
Tim Guidish for Treasurer
Kristin Bonny for Secretary

Regan made a motion to put forward the 4 candidates as stated on the slate for approval to their office. Laurie seconded, all were in favor.

Agency Reports DHHS/Title V: They have a new division director, Melissa Hardey, she is new to the department. It was suggested that we may want to invite her to a meeting to introduce our Council to her and show her how she can use us.

Discussion continued on the ongoing redesign. They are reviewing data and drafting contract language for an interim year. The stakeholder group did not meet in December or January. They are looking into child development programs, the shortage in evaluators/diagnosticians for the child development clinic, and how best to address this problem. Family Voices also has a group looking into provider shortages.

2022 Annual Report Approval: Some edits and suggestions were made, for example, dates in chronological order vs. ongoing. Audrey will wait a couple of days for input and then will submit the report to the printer, then to the Governor.

Needs Assessment Update: The first listening session occurred on Jan 5th. 27 people had signed up but only a small group was able to attend. JSI will put out more reminders in the future. JSI reported that they received great feedback. They put a draft survey together and will be ready to send it out in a couple of weeks. Anyone who has recommendations on who to send the survey out to should let Audrey know. The surveys will be sent out during the month of February. Dee will find out how council members can get access to the survey distribution list.

Website Redesign Update: Nicole, Karen, Regan, and Deodonne are all on the Website redesign committee. They have had 2 meetings so far. We need to fix our logo. First Tracks can do it but it will be expensive. If anyone knows someone who can fix our logo let Audrey know. A couple of possibilities were mentioned. Audrey will send a draft of any new logo to everyone.

Meeting dates for 2022: Third Wednesday of the months in 2022

-March 16

-May 18- key one for website launch and teaser report.

-August 17

-November 16

Action Items:

- Council members need to fill out a financial disclosure form.
- If interested in presenting to NH Leadership about CYCC, let Audrey know.
- Council members should let Audrey know of any recommendations to add to the survey distribution list.
- Let Audrey know if you know someone willing to fix our logo for the web redesign.

Prepared by Kristin Bonny