



YEAH! Council

Youth Educating Adults on Healthcare Youth Advisory Council

Spring 2009

Volume 1, Issue 2

Council Sponsors:

“Where I am Coming from, Where I am Going”

For information on how to join YEAH, or to be on the mailing list please contact us at:

Yeahcouncil@yahoo.com

or

1-800-852-3345 ex 4525

On March 21, 2009 the YEAH Council sponsored their first conference, entitled “Where I am Coming from, Where I am going.” The conference featured our council in panel format for : “Let’s talk about me, a life with disabilities”, facilitated by keynote speaker Jonathan Mooney. The panel answered questions about what it means to be “normal”, what inspires them, what motivates them and what their hopes are for the future.



A presentation by Kaleigh Hansen focused on the importance of Futures Planning.

Our keynote speaker was Jonathan Mooney who talked about growing up with learning disabilities. He discussed the importance of not trying to fit in, but accepting yourself as who you are and helping those around you accept you and

help you to work to the best of your abilities.

Despite growing up with ADHD and dyslexia Jonathan graduated from Brown with honors, and an English Lit degree. He talked about the support he received and how he works to support others. His speech was truly inspirational.

The day was well attended by, and received great evaluations from youth, families and professionals.



Inside this issue:

- Conference Wrap-Up 1
- Website 1
- Transition Coalition Info 2
- Council Info 2
- Transition Tips Save the Dates 2
- Spotlight on..... 3
- Newsletter Sign Up 4

Check out our Website!

www.yeah-councilnh.com



Come Take Our Survey

If you are a young adult between the ages of 18-24 with an on-going health condition we would like your opinions about how you manage your care. We are interested in your transition from pediatric care to adult-oriented health care. We want to know what kind of health care you are getting, how you pay for it, and how you learn about health care. We hope that the results will help other young adults to take charge of their health and health care. The survey only takes 10 –15 minutes. To take the survey click on “**Young Adult Survey**” at www.yeah-councilnh.com If you would like to talk with someone about the survey call Kathy at 1-800-852-3345 ex 4510.

YEAH! Council

Meeting Dates:

YEAH:

June 5th 5:30-8:00

July — to be determined

We will be taking a

summer break in August

— back to work in

September!

Who is the YEAH Council?

The council is made up of: Adam B., Nicole T., Mary D., Zach H., Charles M., Jonathan H., Kalie W., James O. Cordelia W. and Mathew B. and is facilitated by Karin Harvey-Olson. The group comes together monthly to discuss issues involved in what it means to be a young adult with a chronic health condition, and how best to make the transition to the adult healthcare system. We work to educate other youth on how to handle your transition to adulthood, as well as educating the medical professionals about what they can do to facilitate the transition.

Our Mission Statement:

We are here to assist you. We are here to help teens and young adults get the information they need to live independently, to live a successful life and make decisions about healthcare, to inform your doctors and physicians about your healthcare and general needs and make information easily accessible to teens who may lack parental guidance. Our purpose is to help the transition from childhood to adulthood, dependence to independence and pediatric medical care to adult medical care go more smoothly.

Transition Tip

Does your Doctor's office have a policy for transition?

Patience White, MD and the Health and Ready to Work National Resource Center HRTW.org recommends the following:

1. Have a written posted transition policy that states the age when youth should no longer see the pediatrician.
2. Discuss legal health care decision-making prior to youth turning 18.
3. Have youth sign assent forms for treatments prior to age 18.
4. Obtain or develop office forms to support transition processes.
5. Identify a staff person to coordinate transition activities.

Sample forms and policies are available.

Call (603) 271-4510 for resources or email kcahill@dhhs.state.nh.us

Save the Date!

June 19th 6-9

YEAH Council sponsors first Social for youth with Special Health Care Needs ages 16-24!! Join us for pizza and a movie at Dartmouth Hitchcock in Manchester. Check our website for more details.

November 2009

Making Healthcare Transition Part of your Transition Plan

A conference for those working with youth with special healthcare needs.

The "Health Care Transition Coalition" is made up of parents, professionals and youth. It was started in 2006 as a project that worked with pediatricians and young people to learn the transition process, including transfer to adult providers.

The focus has been to get the word out to youth with special health care needs about the importance of learning to manage their chronic conditions and knowing how to get the health care services they needed.

The Coalition is co-sponsored by Special Medical Services and NH Family Voices and was the group that provided YEAH with its start. It meets quarterly and continues to work to get more information out to families, youth and providers about the best ways to improve transition services. The Coalition provides pamphlets, tools for transition and other resources and supports direct consultation to families and providers through staff at SMS and NH FV.

Call 1-800-852-3345 X 4488 for referral to SMS or NHFV.

Hi my name is Cordelia. I am 23 years old. I was born extremely premature in Boston MA and rushed to the neonatal intensive care unit (NICU) where I began to battle for my life. Over the next couple of long months I lived in the hospital where my little body grew strong enough to be able to go home. When finally discharged, I came home with an oxygen tank and feeding tube. We had around the clock support and my family thought I was home for good. But when that did not work out we spent a lot of time in the local hospital. Even though I was healthy enough to go home I still had day trips to Boston. I was involved with Early Intervention and pre-school but it was hard since I was dealing with the chronic illness everyday. The chronic illness always came first so basic things like walking, talking, eating were all delayed.

I started school in Rye. It was very hard having a chronic illness and a learning disability. I was one of the first students in 1992/93 to have full day one to one support staff. I was sometimes pulled out of class to get support in the resource room. I really hated those times since I knew then that there was something wrong with me. Everyday after school was a struggle to get homework done because I was so tired from the day. At times as I also had to deal with my asthma and G-tube. It got better overtime and by 1993 I was just using the oxygen tank at night! Even with all of these issues I loved going to school, but sometime I still had to miss school to go to the hospital in Boston. I wrote my about my trips to Boston to share with my classmates. By then I was an expert on hospitals and I would tell people if they had any questions they should come to me! It was helpful that I wrote about them so that I would be able to look back on these trips years later.

In third grade, I had my g-tube taken out for good. I was really happy and felt I was really getting better! The learning disability continued though and I got pulled out of the classroom for help. There were days when I loved it since I liked working with my teachers. But I also hated running back to the classroom to see what I missed. Then in the 6th grade I found out I have ADD. During middle school I was on medication. I had some minor behavior issues. I was polite most of the time, but not always that great about homework. I liked my classmates and I really like to hang out with my guy friends! I loved going to the middle school dances and it was just a great feeling to be a part of my town. I always had a great sense of humor and they knew how to get me going! As I progressed in middle school, I felt like I was becoming normal since I was doing almost everything the other students were doing. But things would change again.

I left middle school and went to high school. Over the years the gap had gotten bigger between my peers and I. In middle school it was ok but in it high school it was worse. I relied on my childhood to help me cope through the tough times in high school. Then I moved to a different town and it was really hard for me to start at a new school. I thought about my former classmates everyday. I felt like I had to keep a low profile when I moved. It was hard to explain why I moved. I had been on medication for anti-depression since middle school and I struggled with depression in high school. I got bad grades since I never did my homework. I was in low level classes and I hated it. I thought about dropping out of school but with tons of support in special education I was able to complete high school. In the new school I didn't care about being with my classmates. I took an extra year of high school to make sure that I had four years in one high school.

After high school, I struggled for about two years trying to figure out what services I would qualify for. It was a very long process to get the help that I need to support myself. The summer after high school I became depressed again. I went back to my hometown for the last time to see if I could connect with anyone. Sadly my former classmates had left me behind for good. I looked at schools to attend for students who had learning disabilities but decided against it. I wanted my own apartment, I was having problems with my parents and I wanted to move. With support from programs I was able to move in 2008.

It has been a long time since I was sick and I wanted to find out what happened to me as a child so I got a copy of my medical records. I was shocked at what the doctors wrote all those years ago. I knew I was sick at the time, but I did not know how serious it was! I started asking questions about what happened and why. It turned into a couple of years of research and reconnecting with old family friends, working with the March Of Dimes and doing Walk America (now March For Babies) and taking the NH Leadership Series. It also involved long conversations with my family and having stories repeated. I hope that I can be happy in my life since I hate how it felt when I was depressed. A lot people have cared for me over the years and can see how far I have come. They have also support me during the tough times. I am really lucky to be alive! Thanks for taking the time to read my story.

(If you have questions for Cordelia please reach her through the YEAH! website at www.yeah-councilnh.com)

Interested In Receiving this Newsletter?

PLEASE RETURN TO:

NH FAMILY VOICES
129 PLEASANT STREET
THAYER BLDG
CONCORD NH 03301

I would like to receive “YEAH Newsletter”.

This is a **FREE** publication.

Please print

NAME: _____

STREET: _____

CITY, STATE, ZIP: _____

Tel # _____

I am a youth with a chronic illness/disability

I am a parent/family member of a youth with a chronic illness/disability

I am a professional in Health Care Human Services Education

Other _____

Return Service Requested

NH Family Voices
129 Pleasant Street
Thayer Building
Concord NH 03301
yeahcouncil@yahoo.com

Join the YEAH
Council on
Facebook!

We have an active discussion group featuring members of our council as well as youth, professionals and family members from the Greater New England area who have an interest in special health care needs. Come introduce yourself and join in!! Go to Facebook and search YEAH Council.