NF Tennessee Newsletter, Volume 3, Issue 1 Spring 2019

NF Tennessee Newsletter

NF Tennessee's mission is to create a community for persons and families with Neurofibromatosis through support, education, and advocacy.

NF Tennessee Supports Community Events Across Tennessee

NF Tennessee, which started in 2016 with the aim of becoming a local resource supporting the NF community in the Tennessee valley region, has recently reached the milestone of becoming a not-for-profit 501(c)3 designated organization. The steps taken in getting to this point have been slow and steady, and the aim has remained the same: to create a community for individuals and families affected by NF through support, education and advocacy.

Tennessee already has NF communities that function to bring people together to share ideas and experiences, raise awareness, raise funds, and support each other. Individual advocates, local medical teams and national NF organizations have promoted and supported these activities. And the more you look the more you find. Tennessee has had a lot of community events in the last 6 months including major fundraising events for the Children's Tumor Foundation and NF Network. The Nashville NF walk supporting CTF was on September 8, 2018. The Memphis NF walk and 5k run supporting NF Network was on November 2, 2018. Another major fun(d)raiser is the Cupid's Undie benefiting CTF run which was held on February 9, 2019. The upcoming Vanderbilt NF Patient and Family Symposium, and Franklin Theater Concert to Benefit the Children's Tumor Foundation are other examples.

As part of our mission to support our NF community, NF Tennessee has served as a local sponsor for both the Nashville and Memphis NF walks this year. We also fielded a small team in the Cupid's Undie Run. It feels like the NF community in Tennessee is blossoming and NF Tennessee hopes to support further interest and growth. If your group is planning an NF related event and looking for advertising and support we are looking for more opportunities to help.

In This Issue

Nico of #TeamNico. See pages 4-5 for more info and an interview with his mom, Emily.

Visit our website at www.nftennessee.org and email us with any comments, suggestions, or ideas at contact@nftennessee.org.

Clinical Trials News: Ongoing NF2 Trials

- Clinical Trials for NF2 continue to expand with new medications that target different tumor promoting pathways. Selumetinib, which has shown very good results for NF1-related plexiform neurofibromas, is in testing for NF2-related vestibular schwannomas and also for non-VS tumors including meningiomas and other schwannomas. This trial is underway at the University of Cincinnati. For additional details see https://clinicaltrials.gov/ct2/show/NCT03095248?cond=nf2&draw=4&rank=23.
- At least two other medications that target cancer related growth pathways are being considered for clinical trial testing for NF2, Crizotinib and Brigatinib.
- Another ongoing clinical trial is evaluating the use of aspirin to prevent growth of NF-2 related vestibular schwannomas. (https://clinicaltrials.gov/ct2/show/NCT03079999?cond=nf2&draw=7&rank=32)

Clinical Trials News: Vanderbilt University Educational Study Seeking Young People with NF1

Academic underachievement is a common concern voiced by parents of children with NF1. Up to 75% of children diagnosed have poor academic achievement in various subjects, which is much higher than the percentage of children who have learning disabilities in the general population. Reading deficits are a common learning disability among children with NF1.

In a previous research study, researchers explored what type of tutoring program was most beneficial to children and adolescents with NF1. Results from that study suggest they may benefit from a remedial reading program that involves learning the various sounds of letter combinations using a multisensory approach that emphasizes auditory, visual, and tactile processes.

Now, an exciting new research study out of Vanderbilt University builds upon the previous work by investigating outcomes of the reading program when combined with a medication called Lovastatin (Lovastatin is not approved by the Food and Drug Administration for the treatment of reading trouble due to NF1). While previous Lovastatin studies have not shown improved learning in NF1, none have closely mirrored the mouse model studies, in which medication was paired with learning. The current study does this by examining if Lovastatin will enhance learning when an individual is being taught a specific skill.

With enrollment for this study still ongoing, we asked one family to speak about their experience after finishing the study. The participant stated, "I was diagnosed with NF type 1 at age 11. After I was diagnosed, the disabilities I had made sense. When I was younger I couldn't get why things were so hard to make sense of. The one disability that was the hardest to overcome was reading. Everything changed after I was diagnosed, and I was seeing doctors to get lots of scans and participate in different studies. The doctors told me around puberty I might start growing tumors. I now have a quite a few tumors and they are pretty painful. Going to Vanderbilt in Tennessee was really cool. Everyone that I worked with was very fun and so welcoming. My last study visit was on my birthday and the lab staff got me cupcakes and a balloon that I still have. That was really sweet of them." The participant's parent added that the research team was "very organized and did a great job anticipating everything we needed to know ahead of time."

For more study details or information about how to participate in this study, go to: https://vkc.mc.vanderbilt.edu/ebrl/participate/current-study-flyers/

Or contact: educationbrain@vanderbilt.edu or (615) 875-5534.

Check out the calendar on page 6 to learn about some exciting events happening in May and beyond! >>

Recap of the Memphis #NFStrong Family Walk

By Carrie Wylie
Team Kaitlyn
Germantown, TN

<< A great crowd in Memphis, TN, for the #NFStrong Walk.

The Memphis #NFStrong Family Walk creates awareness for the neurofibromatosis community, with great opportunities to enjoy wonderful fellowship with NF families and doctors. The morning starts with registration at 8:00 am, where pre-registered guests each receive a beautiful event shirt and goodies. While waiting for the walk to start, participants, friends, and supporters can enjoy hot chocolate and music, bid on silent auction items, and check out the great raffle items. There are games, crafts and face painting for our little NF Heroes.

The walk/run begins around 10:00 am. Runners have a 5K path to follow. Walkers have a shorter trail to enjoy. Both trails are filled with beautiful fall foliage. As the NF Teams return, they receive an #NFStrong medal and are greeted by super heroes for fun photo ops. Hotdogs and treats are served as guests are entertained by our special guests of My Studio Gray dancers and cheerleaders. Following the performances, the NF Teams are honored with certificates during the awards presentation. Last year, we were honored by the surprise appearance of Mayor Strickland and our UT LeBonheur NF doctor, Dr. Pivnik. Raffles are drawn and auction items are announced as we wind down and our friends and families say their goodbyes.

The Memphis #NFStrong Walk has only gotten bigger in its 10 years. It has grown from around 30 attendees to over 120 in our current year. With 2019 being our 10-year anniversary, we only hope to make it another record year! Overton Park offers a lovely environment for the festivities. The Farmer's Market Pavilion provides a comfortable setting to socialize with new and old NF friends as the teams set up booths around the pavilion to support their NF Hero. Our #NFStrong walks provide a place where everyone can share their story and feel loved and supported, while still enjoying a morning of fun.

The goal of each #NFStrong Walk is to spread neurofibromatosis awareness, while also expanding the NF community. This is an event where everyone is welcome and it's okay to be different. Come join the fun at the 10th Annual Memphis #NFStrong Walk on November 2, 2019!

Acoustic Neuromas Association Patient Event Hosted by Vanderbilt University Medical Center

The Vanderbilt University Medical Center Departments of Otolaryngology and Neurosurgery hosted the Acoustic Neuroma Association (ANA) Patient Education Event on September 29, 2018. The ANA, the premier resource to the Acoustic Neuroma community, informs, educates and supports those affected by Acoustic Neuroma brain tumors. The meeting was organized by Dr. David Haynes Professor of Otolaryngology and Director of the Skullbase Clinic and Dr. Reid Thompson, Chairman of Neurosurgery. Over 300 people attended.

The agenda included individual presentations on topics including surgery and radiation therapy for acoustic neuromas (also known as vestibular schwannomas), rehabilitation therapy, facial muscle reanimation, and Neurofibromatosis type 2. There were also panels discussions that included members of the Neurosurgery, Radiation Oncology and Otolaryngology faculty reviewing cases and discussion treatment options.

Although most patients with acoustic neuromas do not have NF2, there are important overlaps in the types of symptoms and treatment options between the sporadic AN and NF2-related AN patients. Patients with NF2 often look for additional resources beyond the standard neurofibromatosis literature and websites for information about treatment for their acoustic neuromas since these tumors are not part of the NF1 spectrum of tumors. The ANA is an excellent source of more information, support groups, patient events and meeting. This was very evident at the Vanderbilt Patient Event. (see www.anausa.org/latest-news/392-all-enjoy-ana-vanderbilt-patient-event)

For much more information visit the Acoustic Neuroma Association Website at https://www.anausa.org/.

Q&A: Parent Perspective with Emily Tseffos

Emily Tseffos is an NF advocate on the local, state, and even national level. Her son, Nico, was diagnosed with NF1 and has inspired her to advocate on behalf of everyone with NF.

Q: Tell us about Nico. How is he doing?

A: Nico is doing really well! He'll turn two in May and is meeting all of his milestones developmentally. He is engaging, charismatic, smart, and LOUD! We had our last appointments with his specialists this past December and received an all-clear for the year. We'll be back in September for another eye exam.

Q: In first learning about NF1 what were the biggest questions you had? What were the best sources for information for you?

A: The questions we had were endless. Before our initial appointments, we had to do a lot of self-guided research. Luckily my husband has access to medical journals through his job so we utilized those but I did probably too much searching on the internet. Finding the Children's Tumor Foundation and the NF Network were two great resources for our family as we grappled with the news and the uncertainty of the future. I also am a member of several Neurofibromatosis-focused groups on Facebook that offer personal testimonies and experiences, which are helpful.

Q: There are so many variations in NF1-related problems. Have you been able to get a good focus or an overall perspective on the main issues for Nico?

A: This is one of the most challenging aspects of NF1 for my husband and myself. Since Nico's diagnosis we've spent countless hours with our new NF "family," educating ourselves on the possible challenges that may come his way – but you never really know. There's been no genotype-phenotype correlation for Nico's mutation, so the future is still pretty unclear – and scary – for us. What we do know is that as problems arrive we've made a promise to Nico to be the best advocates we can be by surrounding him with experts in the field that will be able to give him the best outcome no matter the challenge.

Q: When a new medical problem comes up for a family, there are waves and ripples in all directions. In this journey for Nico and your family what are the biggest things you have learned so far?

A: Grappling with Nico's diagnosis was a frightening time for Nick and I, and we took a moment to wallow in the grief that served as an indoctrination of sorts into the NF community. We are by no means going to lose our son, but there was a moment in those first days when we realized that our lives as a family had been changed forever, as well as our personal goals and ambitions. The dreams and aspirations we had as individuals have shifted to fill our new role as parents of a person with a rare disease, and for us we learned that advocacy and learning as much as we could about Neurofibromatosis was the best way to deal with the fact that we can't really do anything to help our child.

[continued on page 5]

Q: You have developed a strong interest in NF advocacy. Were you always an advocate? Do you have special qualities or skills that make this a natural thing for you to do? Can anybody be an advocate?

A: I've always been interested in advocacy for a variety of causes, but I'm by no means an expert. I think the biggest lesson that I learned prior to Nico's diagnosis, however, is that if you don't do it no one will. If I don't act as the best advocate and strongest fighter as I can for my son and for others who are challenged by rare diseases, it is not guaranteed that anyone will pick up the slack. Fortunately, I'm an extrovert so more public and visible advocacy is not difficult for me, but I don't have any special skills that make me a better advocate than anyone else. I want to do it and I go about it in the best way I know how. That's the important thing to remember – there is no "correct way" to advocate for something that you hold close to your heart. You do it because it matters to you and because you understand the importance of it.

Q: Can you tell us about the NF programs you have been working on?

A: Last year, I began volunteering to raise funds for the Children's Tumor Foundation through #TeamNico at the Nashville Rock n Roll Marathon – and we ended up raising over $20,000! We were joined by family and friends and it was an amazing weekend.

I also helped my dear friends Pennie Brooks and Jordan Britton with NF Awareness Month (May), getting the Parthenon lit up as well as receiving a proclamation from Governor Haslam to recognize May as NF Awareness month here in Tennessee.

In February I had the opportunity to travel to Washington, D.C. to attend two days of lobbying on Capitol Hill for federal funding for the Neurofibromatosis Research Program through the Department of Defense. We met with staff members from almost all of the Tennessee delegation and I was able to share our family's story as well as all of the great things happening in Tennessee when it comes to our NF community. It was something I hope to be able to mentor a fellow Tennessean that is interested in joining us on the Hill in 2020!

NF Tennessee Resource Page

NF Tennessee is continuing its goal of developing a resource page that covers topics of concern for NF patients and families at the local and state level. We recognize that there are excellent sources at the national level for basic information about NF, such the websites of the CTF and NF Network. Our focus is to have an NF Resource Page that highlights resources in Tennessee. To this end we are partnering with colleagues at the Vanderbilt Kennedy Center, a nationally renowned source for support for children with developmental disabilities and experts in creating resource listing for local throughout the state. One example of their remarkable work is the Tennessee Disability Pathfinder (www.familypathfinder.org). This reaches to every county in the state.

The current plan includes three major areas of resources: Medical, Educational, and Social.

You can help us in this effort! If you have a good resource to share, please send it to us at contact@nftennessee.org.

About Us:

Non-Profit Status:
NF Tennessee is working to develop an active infrastructure to support neurofibromatosis patients, families, and caregivers in the Tennessee Valley region. We are a 501(c)(3) non-profit organization.

Disclaimer:
NF Tennessee is an independent organization and is not affiliated with the Children's Tumor Foundation, the Vanderbilt-Ingram Cancer Center NF Clinic, or Vanderbilt Medical Center, although some NF Tennessee board members are employed by Vanderbilt University (EMW, MK) or Vanderbilt Medical Center (PLM).

Calendar: Upcoming Events in the Local and National NF Community

- Vanderbilt NF Patient and Family Symposium
  - April 13, 2019
  - 9:00 AM to 1:00 PM
  - Preston Research Building
  - Vanderbilt University Medical Center
  - 2220 Pierce Avenue, Nashville, TN, 37232

- St. Jude Rock 'n' Roll Nashville Marathon with Team Nico
  - April 27-28, 2019
  - Downtown Nashville, TN
  - https://www.runrocknroll.com/en/Events/Nashville

- END NF with Ian Desmond Baseball Game – Atlanta, GA
  - Colorado Rockies at Atlanta Braves
  - April 27, 2019
  - 7:20pm - 10:20pm
  - SunTrust Park
  - 755 Battery Avenue, Atlanta, GA, 30339

- A Night of Hope Benefit Concert at Franklin Theatre Featuring Thompson Square
  - Sponsored by the Children's Tumor Foundation
  - May 6, 2019
  - 8:00pm - 10:00pm
  - Franklin Theatre
  - 419 Main Street, Franklin, TN, 37064
  - https://www.franklintheatre.com/all-events/

- May is NF Awareness Month
  - Shine A Light – Nashville, TN
  - Lighting up landmarks in blue and green to raise awareness
  - May 17, 2019
  - Korean War Veterans Memorial Bridge, Nashville, TN
  - https://www.ctf.org/get-involved/shine-a-light

- Children's Tumor Foundation NF Forum
  - Sep 19-22, 2019
  - Hyatt Regency
  - 5 Embarcadero Center, San Francisco, CA, 94111
  - https://www.ctf.org/get-involved/nf-forum

- Nashville NF Walk – September 2019 (Date TBA)

- 10th Annual Memphis #NFStrong Walk
  - Overton Park
  - November 2, 2019

Participants from this year's #NFStrong Walk in Memphis. >>