

# NF Tennessee Newsletter



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

## Vanderbilt NF Patient and Family Symposium Recap

In 2017, the Vanderbilt NF Clinic joined the Children's Tumor Foundation Clinic Network, and one of the biggest opportunities arising from that was the first Vanderbilt NF Patient and Family Symposium. The symposium was cosponsored by the Children's Tumor Foundation and the Vanderbilt-Ingram Cancer Center. About 70 people attended this half-day event on Saturday April 21, 2018. The meeting included multiple presentations, small group discussions, a question and answer session with a panel of experts, and an informal lunch.



*Vanderbilt NF Family and Patient Symposium organizer Dr. Moots with attendee A.J. Brock.*

The program opened with updates on medical issues related to NF1 and NF2 by Dr. Jen Brault and Dr. Paul Moots. A large portion of the program was devoted to NF resources including a presentation by Mrs. Pennie Brooks, the local CTF representative, on CTF resources, Dr. Robert Hodapp of the Vanderbilt Kennedy Center and Peabody School of Education on the Tennessee Disability Pathfinder and Vanderbilt Advocacy Program, and by Mr. Skyler Moots of NF Tennessee who set in motion the NF Tennessee resource development search. The attendees worked in small groups to come up with a list of resources such as websites, brochures, books, or any other sources of information or help that they wish they had. [Continued on page 2]

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*"David Preparing BBQ Beef Brisket"*  
Rachel Mindrup  
2014  
Oil on Canvas  
30"x24"

Visit our website at [www.nftennessee.org](http://www.nftennessee.org) and email us with any comments, suggestions, or ideas at [contact@nftennessee.org](mailto:contact@nftennessee.org).

[Continued from page 1] The results have become the foundation for the NF Tennessee resource program that is discussed separately in this newsletter and will be placed on the NF Tennessee website.

The third part of the program focused on education issues for children with NF. This highlighted laboratory and clinical research programs ongoing at Vanderbilt with Dr. Colleen Niswender and Dr. Rocco Gogliotto of the Vanderbilt Center for Neuroscience Drug Discovery discussing brain biochemistry related to memory in NF1 and Dr. Sheryl Rimrodt-Frierson of Pediatrics/ Development Medicine discussing a clinical trial ongoing at Vanderbilt for children with reading difficulty due to NF1. Ms. Ellen Casale from the Kennedy Center then presented a review of support services and accommodations for children with learning disabilities. The program concluded with a question and answer panel discussion that



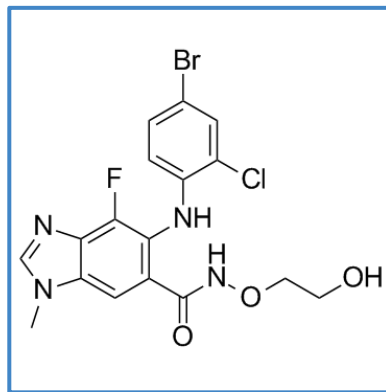
*Several speakers from the Vanderbilt NF Patient and Family Symposium (from right to left): Dr. Paul Moots, Mr. Skyler Moots, Ms. Pennie Brooks, Dr. Jen Brault, and Dr. Sheryl Rimrodt-Frierson*

gave the attendees the opportunity to raise issues of interest for discussion. The feedback from attendees was very positive, and there are hopes of having another symposium in the Spring of 2019.

## Clinical Trials News: Two Trials of Selumetinib

Selumetinib, an oral medication that blocks an enzyme involved in cell growth, also known as a MEK inhibitor, received a lot of attention when it was shown in a clinical trial to shrink some NF1 related plexiform neurofibromas. (see: ClinicalTrials.gov number NCT01362803) The report on this trial appeared in the New England Journal of Medicine in December 2016. Enthusiasm for this medication has led to a series of additional clinical trials for both NF1 and NF2.

*The chemical compound for Selumetinib is shown below.*



Cutaneous neurofibromas are receiving much more attention in terms of research and clinical trials than they had previously. A trial for these skin neurofibromas led by Dr. Bruce Korf is now open at the University of Alabama, Birmingham NF Clinic. "Selumetinib in treating patients with NF1 related cutaneous neurofibromas" (NCT02839720) will enroll 24 patients with NF1 who have a substantial cutaneous neurofibroma burden causing distress by either appearance or itching. Patients must be older than 18 years of age. There must be at least 9 neurofibromas larger than 4 mm. In this trial selumetinib is taken twice a day for up to 2 years.

A separate trial entitled "Trial of Selumetinib in patients with NF2 related tumors" (NCT03095248) will enroll 34 patients, ranging in age from 3 to 45 years, with progressive vestibular schwannomas or with other progressive NF2 related tumors (meningiomas, gliomas, ependymomas). The selumetinib is taken twice a day.

These trials enroll only a small number of patients and often require traveling to the study site for multiple visits. So for a lot of patients they are not practical. Still for those patients

for whom it is feasible and who are motivated, clinical trials can be a way to get state-of-art treatments, and also are a special way to give more to the entire NF community by advancing knowledge.

To learn more about clinical trials for NF a good source is ClinicalTrials.gov. This site, which is sponsored by the NIH and the U.S. National Library of Medicine, includes a page for Patients and Families (<https://clinicaltrials.gov/ct2/help/for-patient>) to help you get started.

## Q&A: Artist's Perspective with Rachel Mindrup

**Q:** How did you come to the idea of the "Many Faces of NF"?

**A:** "Many Faces of NF" was really an accidental project that continues to grow fluidly and organically. As a mother with NF, I wanted to help raise awareness, but I did not really know how to go about doing that. I knew people were running marathons and holding gala events and doing all sorts of fun and impactful NF fundraisers. I do not run and the thought of organizing any large event makes me anxious. I decided, instead, to use Facebook to start meeting adults with NF and see what life was like for them living with the disorder so I could understand its manifestations better. One of the first people I met online was Reggie Bibbs. Not only is he constantly raising NF awareness, he was an energetic and



Rachel Mindrup is a professional artist and Resident Assistant Professor at Creighton University in Omaha, Nebraska. She received her BFA from the University of Nebraska-Kearney and then

continued with atelier studies at the Art Academy of Los Angeles. She received her MFA from the Art Institute of Boston. Her current painting practice is about the study of the figure and portraiture in contemporary art and its relation to medicine.

Mindrup's client list includes: Klewit Corporation, Boys Town, Creighton University, Boys Town National Research Hospital, and the Kansas City University of Medicine and Biosciences. Her artwork is held in many private collections, including those of Primatologist Jane Goodall and Supreme Court Justice Clarence Thomas.



*"Reggie Sipping Coffee"*  
Rachel Mindrup  
2012  
Oil on Canvas  
30" x 24"

happy person who simply had NF, but certainly was not allowing it to define him. Since he was raising awareness and I was not doing anything, I asked to paint his portrait as a "thank you" for everything he was doing. He liked it. He used it as his FB profile picture and told me of others who were raising awareness. It quickly turned into a FB profile picture project. After I had done about 15 - 20 watercolors, a NF mom asked me to put them all in one place. Hence Many Faces of NF on Facebook. That was in 2010.

**Q:** Over your career as an artist and painter what kinds of art, artworks, or artists have you found most inspiring? Do these show up in the "Many Faces of NF"?

**A:** The artists I have found inspiring over the years tend to always be those whose images contain a narrative. As a child, I was drawn to the illustrations of N.C. Wyeth and Howard Pyle. I did not know the artist's names, but their paintings of pirates and figures always made me want to read the stories and I would find time to just stare at the paintings. As I grew older, I also became aware of the style of painting

that I preferred. I love representational painting, but I also love when paintings look like paintings. Not that realism isn't a great talent, but I am truly drawn to looking at a painting and then being able to go up close to it and see those individual strokes. Like a patchwork quilt, great brushstrokes knit together to make an amazing modeled form. John Singer Sargent is one of my favorite figurative painters. For me, he took what could be just another portrait commission of just another rich patron and always transformed them into works of art worth gazing at. I would like to say that these influences show up in my work, but I am also the summation of many wonderful art teachers too, so I feel their collective presence when I work.

**Q:** Your website statement about the "Many Faces of NF" talks about portraying personalities. When you first start to paint a portrait is there a lot of conscious study or strategy, or is it a spontaneous process? Can you describe some of the artistic basics of the portrait techniques you have studied and use, and how they are used in some of the NF portraits?

**A:** Because I work from photos, there just is not a lot of room for spontaneity, unfortunately. When working from life, an artist has more room to be a bit more free. For this project, the NF adults ask a friend or relative to take photos of them doing the activities they enjoy. I typically use the works of Vermeer to show them how I want the lighting on the model and that the person should not be looking at the... [Continued on page 4]



[Continued from page 3] ... camera. Once I get the photos, I go through them seeing what I can use. Many times I simply ask the participants for new photos and I will sketch out the composition for them. Other times, I will piece together aspects of different photos and come up with a pencil sketch. If they like the pencil sketch, I will do the painting in oil. I always tone my canvas, lightly draw in charcoal first, seal that in, and then begin painting.

**Q: When you meet someone with NF casually, do you tend to see them in the framework of portraiture technique? Do you see things that non-painters would not see? You have done a lot of NF portraits. Do you find that people with NF are reluctant or nervous about being painted?**

**A:** Yes, when I meet anyone with NF, I am usually looking at them wondering how I would paint them and as we talk and they share more about themselves, the paintings start to reveal themselves to me. I will sometimes jot notes down later in case I ever do their portrait. It is presumptuous to assume that everyone with NF would want to be a part of this project. I have had great success with men, but sometimes women can be reluctant because of the beauty-dominated culture we live in. Many of the people I am painting now were nominated as NF Heroes on my FB online poll.

**Q: Please tell us how your subjects have felt about their portraits? What are the kinds of reactions you get?**

**A:** As far as reactions, I think because it is not a commission, I have only received positive responses. I know very well that if it was a commission that was being paid for, the client would have more changes and so forth. I have done illustration and commissions for years and that is just part of the process, but with this, it really is a non-commissioned oil portrait, so most people are just very appreciative. I invite them to use the painting in whatever capacity they would like. Most use it to help raise NF awareness.

**Q: Please explain how the "Many Faces of NF" can be used to teach about NF and to raise funds. What are your goals with this project?**

**A:** I use the paintings simply as a vehicle to start dialogues about NF. I have been very lucky that academic institutions, colleges, universities, and art centers have hosted my exhibitions. I am invited to speak to the public, speak to college classes, speak to medical students, anyone I can about NF. I am simply making introductions to amazing people via oil paint. The reason I believe this works is because the non-affected population will wander into an art gallery and instantly be surprised that all the people on the wall have the same genetic disorder when they certainly do not have any sort of "look". There is no look to NF, that is why it is hard to explain and hard to raise awareness for.



*"Anne Running the Boston Marathon"*  
Rachel Mindrup  
2016  
Oil on Canvas  
30" x 24"

For more information, please visit:

[www.rmindrup.com](http://www.rmindrup.com)

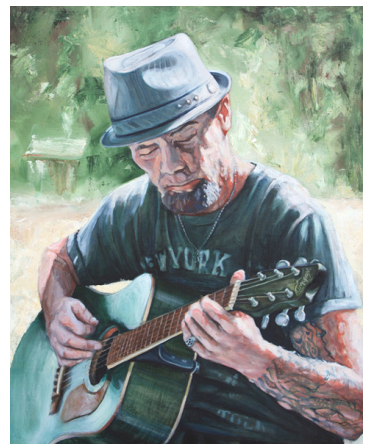
[www.facebook.com/ManyFacesNF/](https://www.facebook.com/ManyFacesNF/)

For the Artist Talk on the Exhibition:

[www.youtube.com/watch?v=7-ywVQmnGCo](https://www.youtube.com/watch?v=7-ywVQmnGCo)



*"Kevin Leading the Charge"*  
Rachel Mindrup  
2017  
Oil on Canvas  
30" x 24"



*"Frank Playing Guitar"*  
Rachel Mindrup  
2016  
Oil on Canvas  
30" x 24"



*"Cecile Playing Badminton"*  
Rachel Mindrup  
2016  
Oil on Canvas  
30" x 24"



## **Resources:** A Request for Your Knowledge

NF Tennessee has a new, big project that we want your help with: developing a list of local resources that you can use. A big part of the Vanderbilt NF Symposium was devoted to talks on resources for NF patients and families: where to get information, where to get help for specific problems. When the people attending the meeting were asked what resources they wished existed the list was pretty long.

- Support Groups/Social events (family, teen, adult)
- Awareness/Education: health literacy, translation
- Doctor and Clinic Database
- Insurance/funding support
- Kids camps
- Parent Guide: Step by Step
- “How To”: Managing everyday life; “new normal”
- Patient stories
- Teacher/Parent Awareness-Engagement: Advocacy, IEP, peer/student education (ensuring parents know what is available)
- Enhanced physician collaboration—multi-disciplinary approach
- Credible online information
- Knowing if it is NF or normal delays
- Vocational support: transitioning from job to job
- Transportation
- Evidence-based modalities/alternative vs. complementary
- Enhanced social media/calendar of events
- Clinical trials database: local, national, worldwide

Many of these resources can be found on websites for national organizations like the Children’s Tumor Foundation and the NF Network. Getting that kind of information for Tennessee or even more specifically for east or middle or west Tennessee is often hard to do. NF Tennessee is aiming to help with that by developing a database of local resources for NF patients and families. We have enlisted help from friends in the Vanderbilt Kennedy Center and the Vanderbilt Ingram Cancer Center. But to really put together a useful list we need your help!

If there are important NF issues or problems that you cannot find resources to help teach or guide you, we would like to know. We will try to find them, or get you in touch with people who will know how to find them. If there are resources that you use and think would be helpful for other people to know about please send them to us also at [contact@nftennessee.org](mailto:contact@nftennessee.org).

The more you think about it, the longer the list of issues becomes. And we think the more you think about it the longer the NF Tennessee Resource database will become.

# Calendar: Upcoming Events in the Local and National NF Community

## • CTF NF Walk - Nashville

- September 8, 2018
- Edwin Warner Park, Shelter 5
- 11:00am, Walk starts at 12:00
- 50 Vaughn Road
- Nashville, TN 37221
- Free Registration:
- <https://join.ctf.org/event/2018-nf-walk-nashville/e184952>



## • Acoustic Neuroma Association Patient Education Event at Vanderbilt University

- September 29, 2018
- 7:30am - 3:30pm
- Langford Auditorium
- 2209 Garland Ave.
- Nashville, TN 37232
- Free Registration:
- <https://www.anausa.org/programs/patient-event-vanderbilt>

## • #NFStrong 5k Walk/Run for Neurofibromatosis (flyer above)

- November 3, 2018
- 9:00am - 11:30am
- Overton Park - East Parkway Pavilion
- 389 E. Parkway N.
- Memphis, TN 38112
- <https://www.nfnetwork.org/events/nfstrong-walk-memphis-tn-1>



## About Us:

### NF Tennessee Board of Directors:

- Dr. Paul L. Moots, M.D., President
- Ms. Elizabeth M. Wright, Vice President and Treasurer
- Mrs. Pennie Brooks, Secretary
- Mr. Theodore Goodman, J.D.
- Mr. Mitchell Korn

### NF Tennessee Staff:

- Mr. Skyler Moots, Chief Operating Officer and Newsletter Editor

### Consultants:

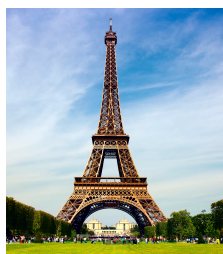
- Thrive Creative Group (Clarksville, TN)
- Mr. Mark Moots, Jr., C.P.A.

### 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 in the process of applying for 501(c)(3) non-profit status, although that has not been established yet.

### 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).



## • 2018 CTF NF Joint Conference

- November 2-6, 2018
- Paris, France
- Maison de la Chimie
- [www.ctf.org/get-involved/nf-conference](http://www.ctf.org/get-involved/nf-conference)