

# NATURAL HISTORY STUDY OF CUTANEOUS NEUROFIBROMAS

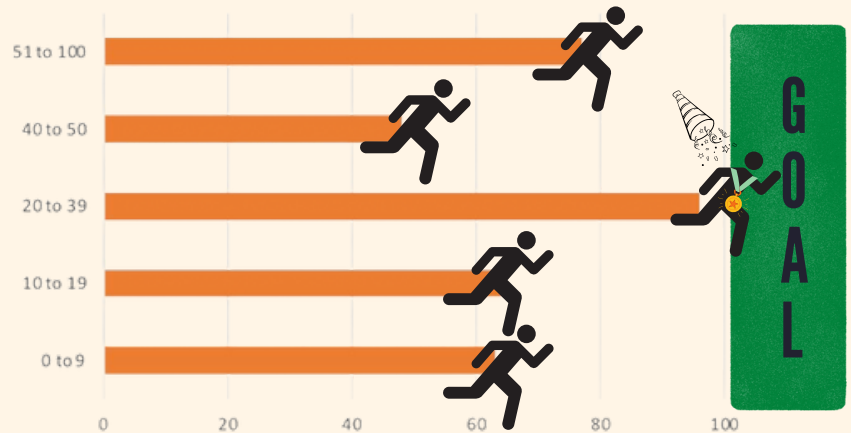
QUARTERLY NEWSLETTER



## WE NEED YOUR HELP! LAST CALL FOR PARTICIPANTS!



WE ARE GETTING CLOSE TO REACHING OUR  
GOAL OF 500 PARTICIPANTS! BUT WE NEED  
YOUR HELP, ESPECIALLY WITH PROMOTING  
THIS STUDY TO PEOPLE WITH NF1 THAT ARE  
**AGES 0-19 AND 40-100.**



We are so close to learning more about cutaneous neurofibromas and your participation and resilience inspire us to keep powering on to find out more!

## QUOTES FROM OUR STUDY FAMILY

"I have seen the progress made over the years and am always happy to participate. I am excited for what is to come."

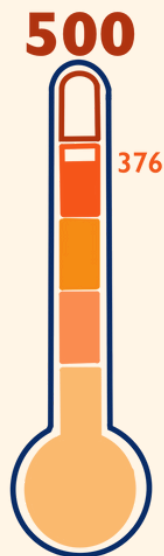
"Everyone living with NF deserves the greatest quality of life and I feel participating in research can assist in making this possible."

"Hopefully this study can determine who is more prone to getting CNFs, when during the lifespan, and where on the body they most commonly occur."



To participate, contact Mandi Johnson at [ajohn418@jhmi.edu](mailto:ajohn418@jhmi.edu) or call 410-929-3551

# PARTICIPANT ENROLLMENT



- **Our goal is to enroll 500 participants by August 2024.**
- **Thanks to you, we are getting closer every day!**

## PLEASE WELCOME OUR NEW AMBASSADORS

- We have developed a new program in our study, and we are looking for participants to act as ambassadors and to raise awareness about this project and help grow our study family.
- Our Ambassadors will also be the first ones to learn about any study results and join regular meetings with our team.
- If you are interested in joining our select group of ambassadors, please contact Mandi Johnson at [ajohn418@jhmi.edu](mailto:ajohn418@jhmi.edu) or call 410-929-3551.

## MEET OUR SPONSOR: NTAP

**This study is funded by NTAP!**

- NTAP stands for “Neurofibromatosis Therapeutic Acceleration Program”.
- NTAP is a philanthropically funded organization within Johns Hopkins in Baltimore, MD.
- The mission of NTAP is to focus on the development of treatment for people with NF1, to foster collaborations, to promote sharing of research data, and to help streamline research related to NF1.
- In the last 10 years NTAP has revolutionized the NF1 field by supporting researchers and clinicians interested in NF1.
- NTAP collaborates with everyone invested in NF1 research including industry, government, academic institutions and patient support organizations to reach the goal of meaningful therapies for people with NF1.

# OUR GOALS

**We have multiple aims that will hopefully inspire new treatment options for cNFs.**

- To study how cutaneous neurofibromas (cNFs) form and change over time in people with NF1
- To identify people who might be at higher risk of developing a large burden of cNFs
- To evaluate how cNFs affect people with NF1
- To search for correlations between the burden of cNFs and specific NF1 genetic variants (mutations)
- Explore a new way of monitoring cNFs by using whole-body 3D photos

## UPDATES

- As of May 2024, a total of 376 people with NF1 are part of our study family. We are very proud that this is the largest and most diverse natural history study of cNFs ever.
- The youngest participant is 10 months old and the oldest participant is 91 years old.
- There are 91 men, 145 women, 61 boys, and 79 girls participating.
- cNFs may change during pregnancy and we are now inviting pregnant women with NF1 to come for extra photographs to track if they develop any skin changes.
- We are working hard to develop tools that can help us diagnose tumors earlier. These tools are called biomarkers. People in our study family are now part of this important effort. Thank you!
- Due to our travel reimbursement program, 47% of participants visit us from outside of Maryland.
- Some of the information that we have learned so far thanks to you will be presented next month in the largest international NF research meeting in Brussels, Belgium.



# VISIT THE NATIONAL AQUARIUM



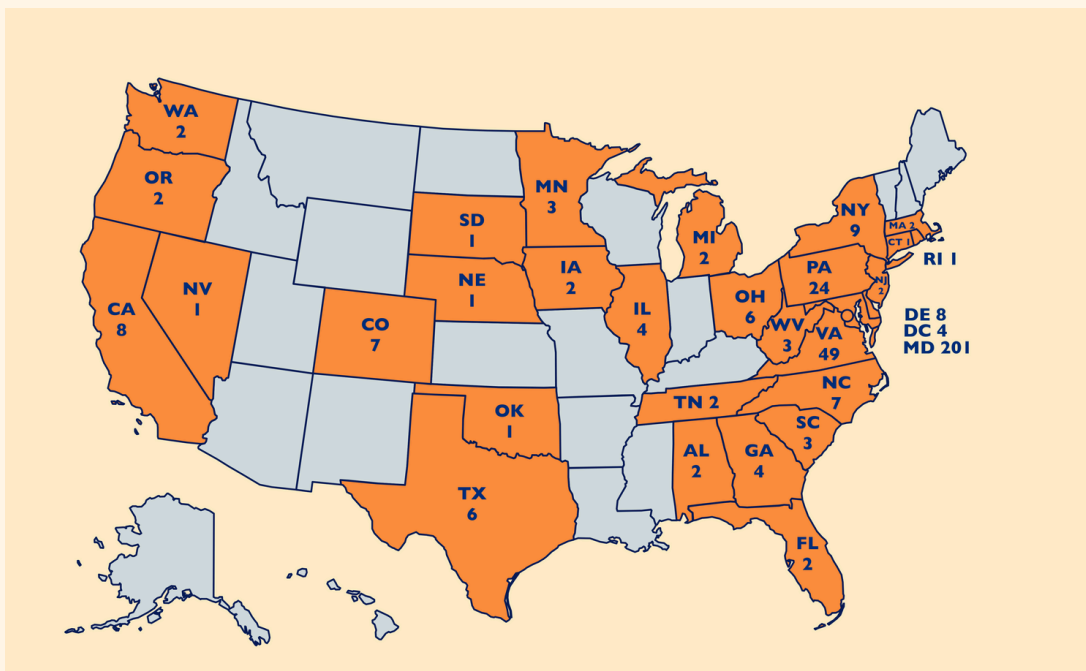
Participants in the CNF Natural History Study and guests receive 20% discount on admission at the National Aquarium. Located just 10 minutes away from us! To [purchase tickets](#) use passcode **Econ2956**.



# SPOT THE DIFFERENCES



# OUR PARTICIPANTS COME FROM ACROSS THE US



*Thank you!*

It has been our pleasure to meet everyone who is part of this project! People with NF1 from 30 states and 3 countries are now part of our study family. We are truly thrilled to see you in Baltimore for your yearly visits! Thank you!

If you are new to this study or would like to learn more about our research study, please scan the QR codes below:



To learn about other NF research opportunities, please visit: [www.hopkinsmedicine.org/nfresearch](http://www.hopkinsmedicine.org/nfresearch) or scan QR code below:

