# NBIAcure NEWSLETTER

- JULY 2019 -


## Clinical Discussion Format

At the 2019 NBIADA Family conference we tested a new format for clinical discussion. In the past, newly diagnosed individuals were able to schedule informal meetings with Dr. Hayflick, Dr. Hogarth, and other experts prior to the start of the conference. However, this became harder to do as the number of individuals diagnosed with an NBIA disorder increased each year. Also, this format didn't allow returning individuals to meet with the doctors to discuss clinical care issues.

Therefore, this year we held clinical meetings dedicated to each NBIA disorder. Anyone with that condition and their families were encouraged to attend (whether they were newly diagnosed or not) and they were given the opportunity to ask clinical questions of Dr. Hayflick, Dr. Hogarth, and specialists such as Dr. Paul Kotzbauer, Dr. Jenny Wilson, Dr. Sucheta Joshi , Dr. Kirsten Campbell, and genetic counselor Allison Gregory.

We hope this gave everyone the opportunity to have their own questions answered and also get to hear the answers to other people's questions. Many interesting discussions were initiated, and this format allowed us to invite doctors with expertise in the most relevant areas.

Please let us know what you thought of the new format.

## Doctor Training Sessions

In order to educate a new generation of doctors about NBIA disorders, five physicians from around the country were invited to the family meeting for a 3.5 hour intensive training session. These doctors had the opportunity to each meet one-on-one with nine individuals with NBIA and their families in order to discuss their diagnosis and do examinations. They were able to see a broad range of diagnoses and ages tailored to their specialties. We hope this experience will enable them to recognize more NBIA diagnoses in the future, serve as NBIA experts at their home institutions, and increase awareness of NBIA nationwide.

We were pleased to be joined by: Dr. Sucheta Joshi from CS Mott Children's Hospital in Michigan, Dr. Migvis Monduy from Nicklaus Children's Hospital in Florida, Dr. David Ritter from Cincinnati Children's Hospital in Ohio, Dr. Laura Tochen from Children's National Hospital in Washington DC, and Dr. Jenny Wilson from Oregon Health & Science University.

## Update On Blood Samples

We want to give a big THANK YOU to everyone who stopped by the blood draw station at the meeting to give samples for research. We were so impressed with your patience and willingness to try again when a blood draw didn't go as planned. All of the samples arrived safely back in our lab, and Dolly worked hard to process them while we were at the meeting.

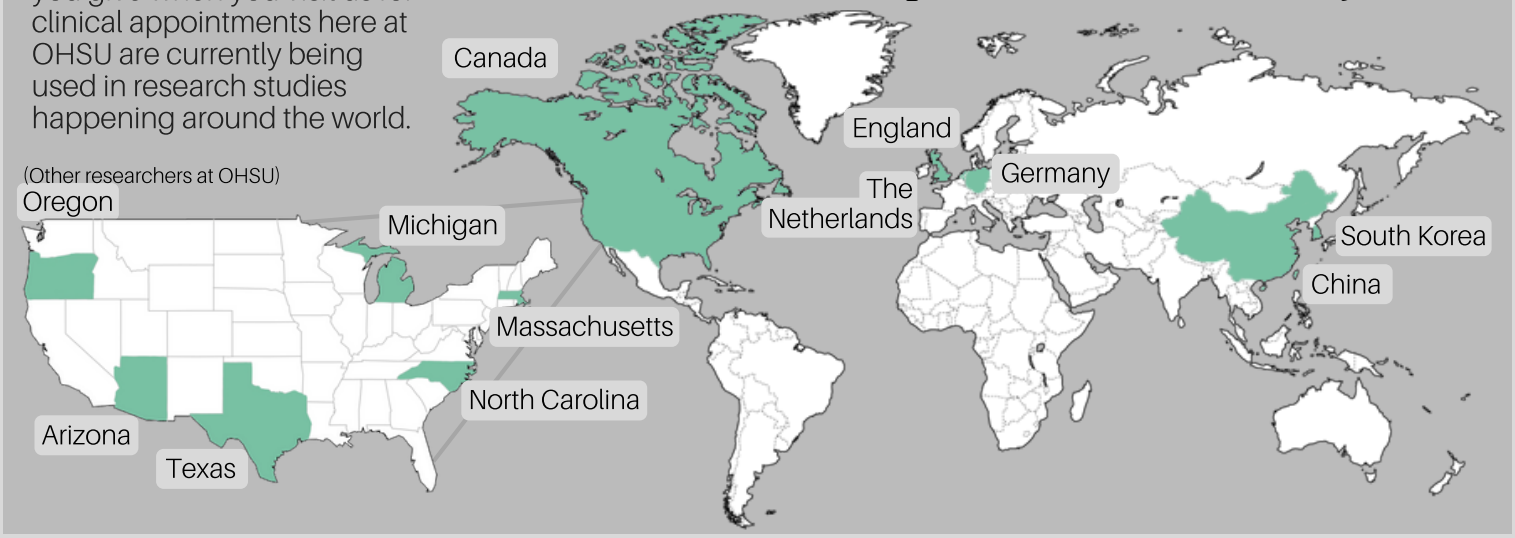
Some of the samples will be sent or have already been sent to researchers around the world who are studying NBIA disorders. The rest of the samples are in our lab ready to be used in future studies. Thank you for your invaluable gift!

# Global NBIA Collaboration

Many families ask us what happens to the DNA/blood samples and natural history data we collect and whether we share that material with other researchers. We use the samples and data for the research we do at OHSU to better understand NBIA disorders and find treatments, but we also share them with researchers nationwide and worldwide. To give you an idea of the collaborators we send anonymized material to, the map below shows all the locations to which we've sent DNA/blood samples and/or data in just the past year and a half!

Some of these researchers are collaborators we've worked with for years and others are new researchers or researchers who are just starting to take an interest in NBIA disorders. The samples we collect at the family meetings and the samples you give when you visit us for clinical appointments here at OHSU are currently being used in research studies happening around the world.

## Locations where data/samples have been sent since Jan 2018




## It was wonderful to see you at the 2019 NBIADA Family Conference!