

Patient Representatives

Patient Representatives Group

Chair: Vanessa Merker, PhD

Past Group Chair: Andrea Gross, MD

Patient Representative Co-Chair: Andrés Lessing, MBA

Patient Representative Co-chair: Claas Röhl

This working group is dedicated to facilitating the engagement of individuals with NF1, NF2, and Schwannomatosis and their family members in REiNS. The first cohort of 30 REiNS patient representatives was selected through an application process in the fall of 2017. This group now serves as a forum to provide feedback to other REiNS working groups on their ongoing projects, and is in charge of organizational planning for continued patient engagement in REiNS, including the recruitment of new patient representatives, education and training of REiNS members, fundraising, and meeting planning.

For more information about REiNS, please click [here](#) to watch a video.

As patients and caregivers of those with Neurofibromatosis 1, Neurofibromatosis 2, or Schwannomatosis, your voices and lived experiences play an important role in determining the direction that research should take. The REiNS (Response Evaluation in Neurofibromatosis and Schwannomatosis) Collaboration is looking for patients and caregivers to help in the fight to cure NF by helping to design clinical trials. This is a chance for you to make a real difference in the future of research for these conditions. A scientific background is not necessary – lived experience with neurofibromatosis or Schwannomatosis is. We welcome people from all backgrounds including people of all genders, races, ethnicities, education level, and disability status. We believe that all voices enrich our research and that diversity maximizes the reach and value of our work.

If you are interested in joining the patient representative program, you can learn more about what the role entails [here](#).

Click Here for a Working Group Snapshot

Patient Representative Recruitment Subcommittee

Chair: Andrés Lessing, MBA

The REiNS Patient Representative Recruitment Subcommittee is focused on planning and implementing the recruitment efforts for the next wave of REiNS patient representatives. This group is looking for current members to help in this upcoming process. Please contact Andrés at alessing@gmail.com if you are interested in participating in this committee.

Patient Representative Education Subcommittee

Chair: Claas Röhl

The REiNS Patient Representative Education Subcommittee is focused on developing an educational curriculum for REiNS' patient representatives. This group is working to review and develop both online and in-person sessions and plan to include information about the design and conduct of clinical trials in general, as well as NF/Schwannomatosis specific topics. They are always happy to have new members from the larger working group to help provide input and feedback on our educational plans. Please contact Claas Röhl at claas.roehl@nfkinder.at if you are interested in participating in this committee.

Patient Representative Dissemination Subcommittee

Chair: Miranda McManus, MS

The REiNS Patient Representative Dissemination Committee aims to provide accessible summaries of all REiNS publications and REiNS recommended measures. While the primary audience for these efforts are REiNS patient representatives and NF researchers who are not familiar with the group's previous work, we hope these summaries will also be useful to all people with neurofibromatosis and schwannomatosis, especially those who may choose to participate in clinical trials. Please contact Miranda at mcmnusm@charleston.edu if you are interested in participating in this committee.

Patient Representative Publications

1. Vanessa L. Merker, Andrés J. Lessing, Irene Moss, Maureen Hussey, Beverly Oberlander, Traceann Rose, Raquel Thalheimer, Tracy Wirtanen, Pamela L. Wolters, Andrea M. Gross, Scott R. Plotkin. Enhancing Neurofibromatosis Clinical Trial Outcome Measures Through Patient Engagement. *Neurology* 2021. Aug 2021; 97 (7 Supplement 1) S4-S14; DOI:10.1212/WNL.0000000000012430. [\[PDF\]](#)

Patient Representative Training Materials

The REiNS education sub-committee together with the Children's Tumor Foundation Patient Engagement Program compiled this group of informational resources to support you in your role as a patient representative. These resources are available for immediate download, print, or watching via video links (click the link below).

[Click this link for informational resources to support patient representatives](#)

Additional Training Materials



EUPATI cover letter.pdf



EUPATI Core Educ... REiNS (002).pdf



EUPATI Additional Reading.pdf