

Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

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REiNS Patient Representative Group Update

Vanessa Merker, PhD
on behalf of the REiNS Patient
Representative Working Group



Response Evaluation In Neurofibromatosis Schwannomatosis
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Patient Representative Recruitment 2.0

Fall/
Winter
2020

- Recorded an introductory webinar on YouTube
- Wrote formal patient representative role description
- Simplified online application

Jan./Feb.
2021

- Advertised new recruitment (n=51 applicants)
- Held live recruitment Q+A and new member social

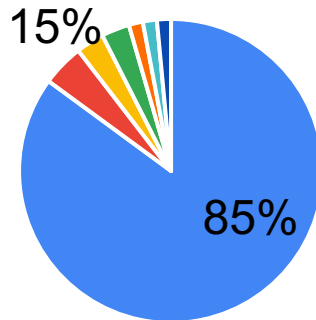
Spring
2021

- New representatives joined meetings in March 2021
- Scheduled alternating meeting times and recording meetings to facilitate participation



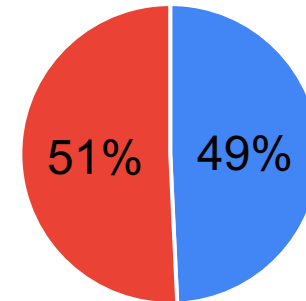
REiNS Patient Representatives (n=67)

Country of Residence



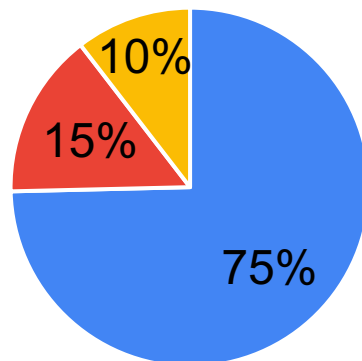
■ USA ■ United Kingdom ■ France ■ The Netherlands ■ Austria ■ Canada ■ Cyprus

Representative Type



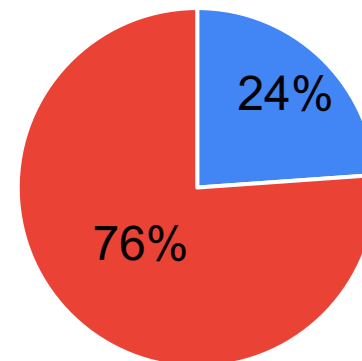
■ Person with NF
■ Family Member/Caregiver

Type of NF



■ NF1 ■ NF2 ■ SWN

Gender

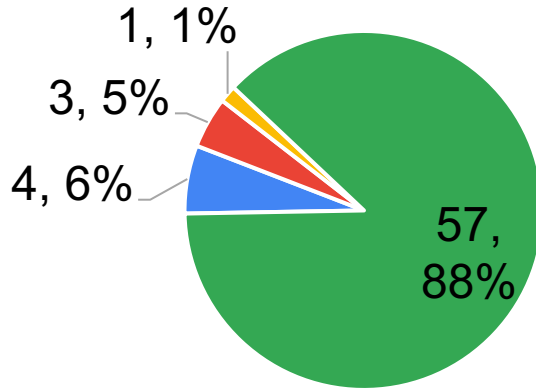


■ Male ■ Female



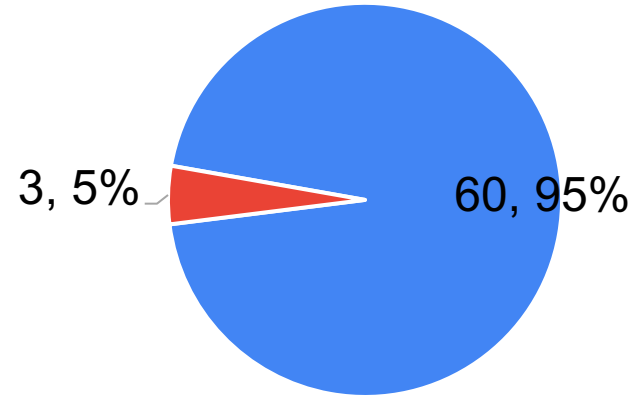
REiNS Patient Representatives (n=67)

Race



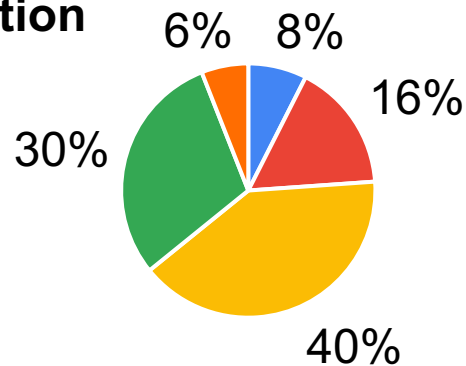
■ Black ■ Asian ■ Native American ■ White

Hispanic/Latinx Ethnicity



■ Not Hispanic/Latino ■ Hispanic/Latino

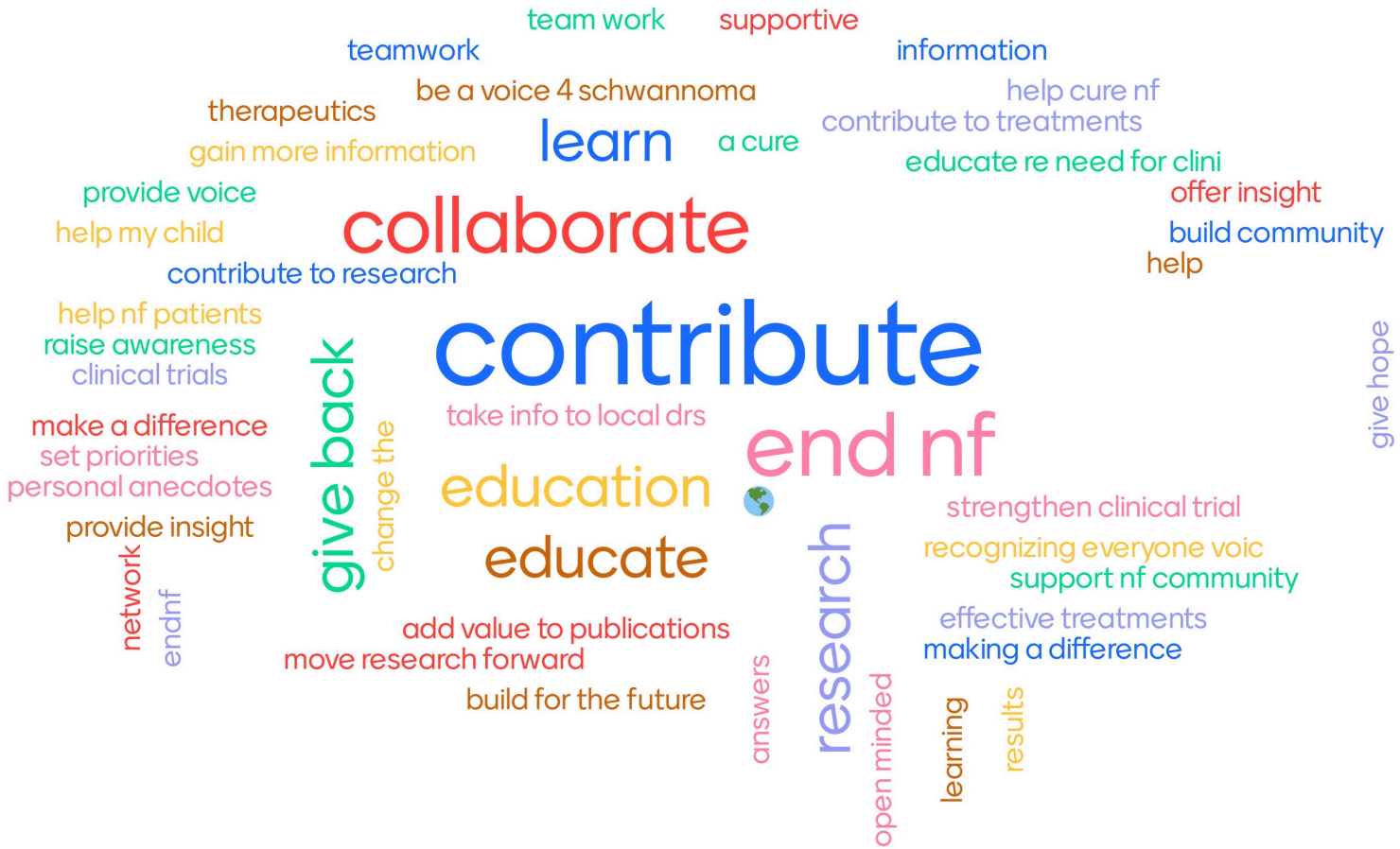
Education



■ High School Degree or equivalent
■ Some College
■ 2 or 4 year college degree
■ Master's Degree
■ Doctoral Degree



What do you hope to accomplish by being a REINS patient representative?



New Educational Training Materials

Glossary of Neurofibromatosis and Medicine and Research

1. [Neurofibromatosis manifestation list with short definition/explanation](#)
2. [Glossary of medicine and research](#)
3. [NF Registry Glossary](#)

REINS

1. [About REINS Patient Representative Program](#)
2. [REINS Frequently Asked Questions](#)
3. [REINS International Collaboration](#)
4. [REINS Working Groups](#)
5. [REINS Presentations](#)

About Clinical Trials

- [What is a clinical Trial?](#)
- [Clinical Trial Phases](#)
- [Deciding to participate in a clinical trial](#)
- [Clinical Trials for NF](#)
- [Clinicaltrials.gov](#)
- [Clinical Trial Endpoints \(fda.gov\)](#)
- [Clinical endpoint - Wikipedia](#)

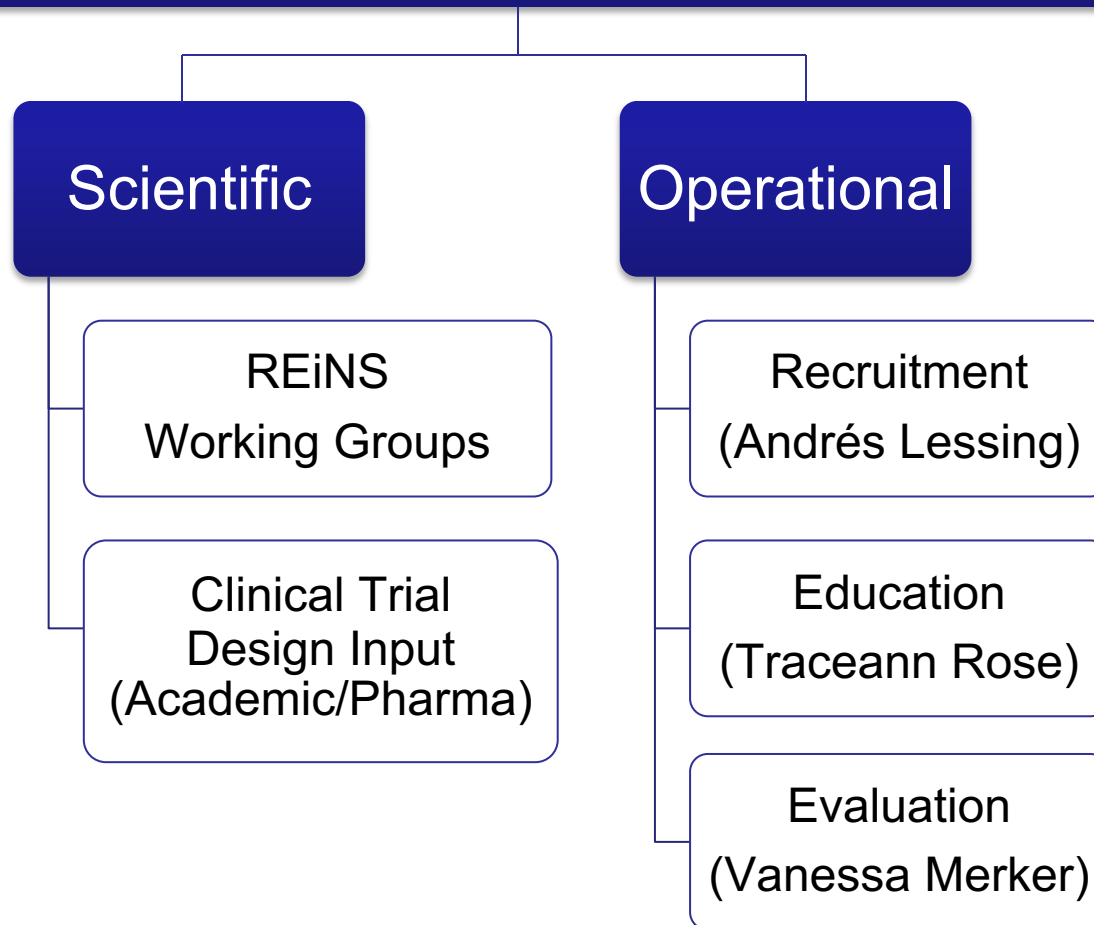


<https://docs.google.com/document/d/1se0B26to0k0yK1589M90Ex4xJq7hMBe11Vt6q61CbEQ/>

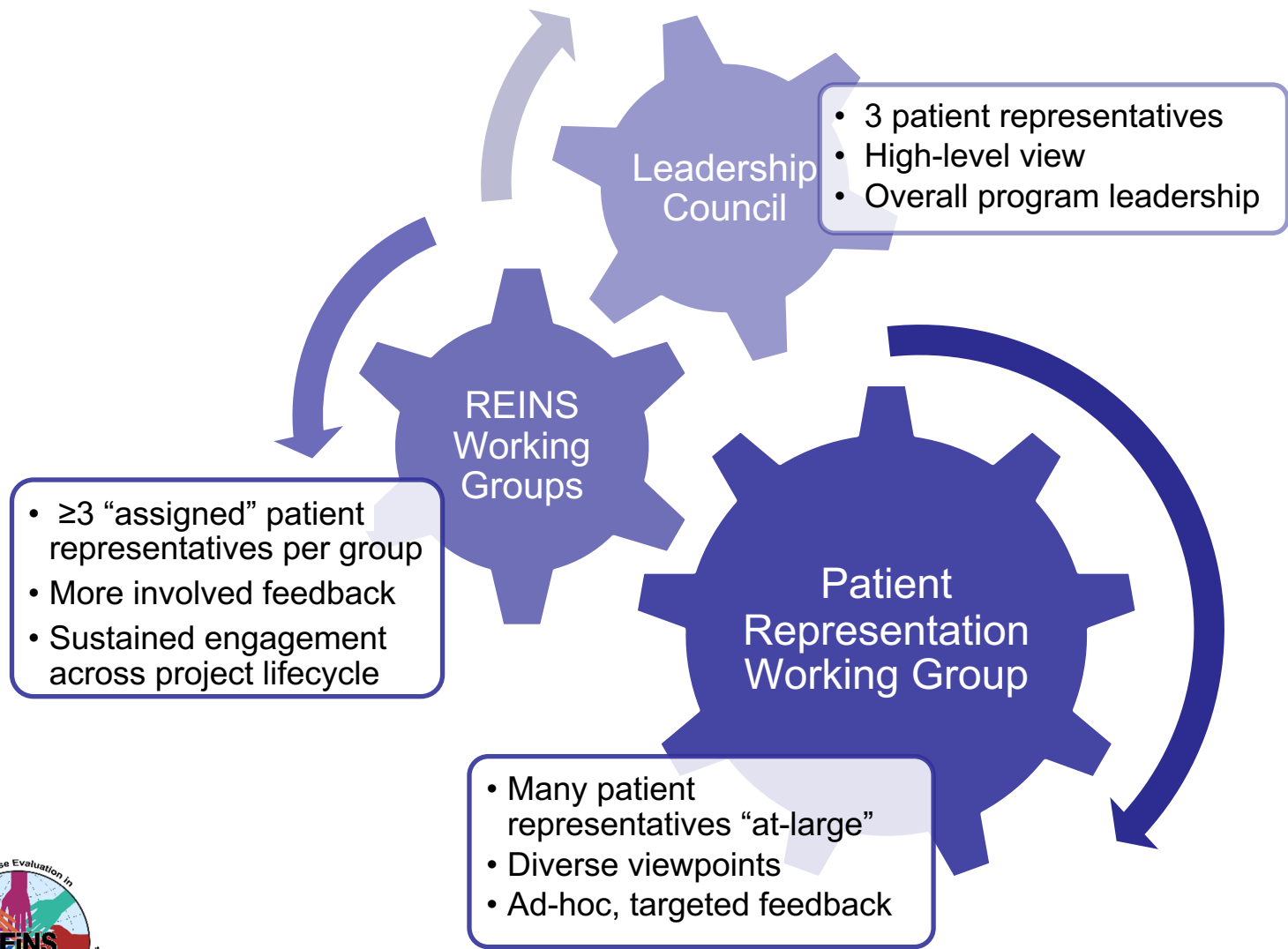
REiNS Patient Representative Working Group

Researcher Co-Chairs: Andrea Gross, Vanessa Merker

Patient Representative Co-Chairs: Andrés Lessing, Claas Röhl



Patient Engagement in REiNS



Patient Representative Feedback on Research Studies

Presenter	Topic
Liny John/Andrea Gross	Disfigurement Rating Scale (Observers)
Heather Thompson	Communication difficulties survey
Andrea Gross	PN Secondary Prevention Trial
Staci Martin	Disfigurement Rating Scale (Patients)
Rob Avery	Vision Restoration/ Vision Preservation Therapies
Karin Walsh	Sleep survey
Vanessa Merker	Grant proposal to embed qualitative interviews in NF Clinical Trials
Brigitte Widemann/Aerang Kim	MPNST triple combination therapy trial
Andrea Gross/Jonathan Rios	Prospective study of MEKi effects on bone



To present your NF clinical trial or related research study, email us at andrea.gross@nih.gov or vmerker@mgh.harvard.edu. Open to all!

Patient Engagement

Patient representatives

- have a unique perspective compared to clinicians and researchers
- can share personal experience and reflect on larger patient community's experiences

Direct Contributions

Perform research tasks

- help determine research focus
- review existing outcome measures
 - give input on study design, recruitment plans & data collection
 - help analyze data
 - disseminate findings



Indirect Contributions

Help clinicians and researchers

- understand patient concerns
 - see the bigger picture
 - work across disciplines
 - communicate more clearly

Research Impact

Improved clinical trial outcome measures

- more relevant to patients' concerns
 - more feasible to implement
- less burdensome on patients to complete
 - easier for patients to understand
 - more meaningful to end-users

Next Steps

- Write Plain English Summaries of REINS manuscripts
- Continue to update educational materials on REiNS website
- Addressing additional priority items
 - Develop a ‘best practices’ handbook for patient engagement including presentation template
 - Conduct follow-up evaluation of patient representative program



Patient Representative Group



What are the most important values for a program to engage patients and their family members in research?

