



Response Evaluation In Neurofibromatosis Schwannomatosis INTERNATIONAL COLLABORATION

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REiNS Patient Representative Program 2.0

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



Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

How We Got Here

Sept.
2019

- Administer evaluation survey (n=63)
- Preliminary analysis

Dec.
2019

- Present findings at REiNS Winter Meeting
- Group brainstorming

Winter
2020

- Turn recommendations into action items
- Write up evaluation findings in manuscript

Spring
2020

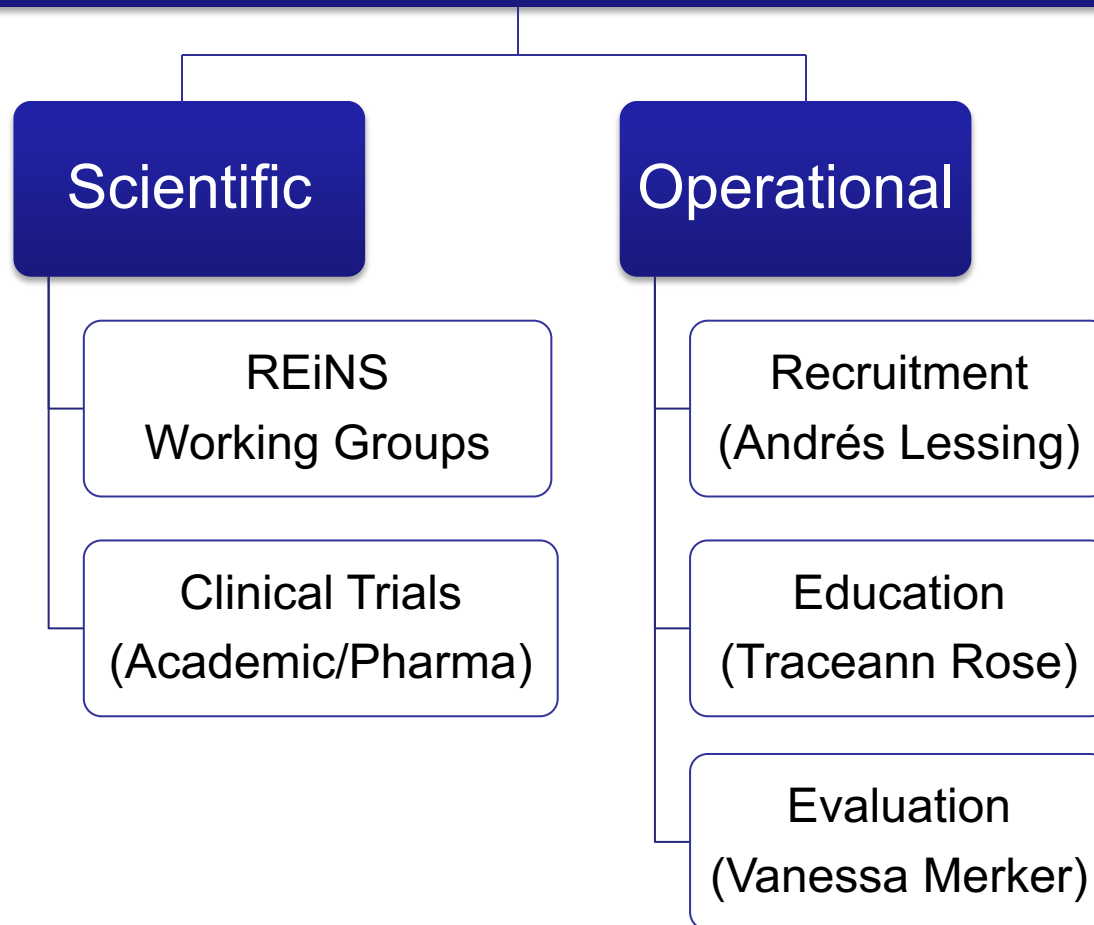
- Envision REiNS Patient Representative Recruitment 2.0
- Pilot patient representative co-chair role



REiNS Patient Representative Working Group

Chair: Andrea Gross, Co-Chair: Vanessa Merker

Patient Representative Co-Chairs: Andrés Lessing, Claas Röhl

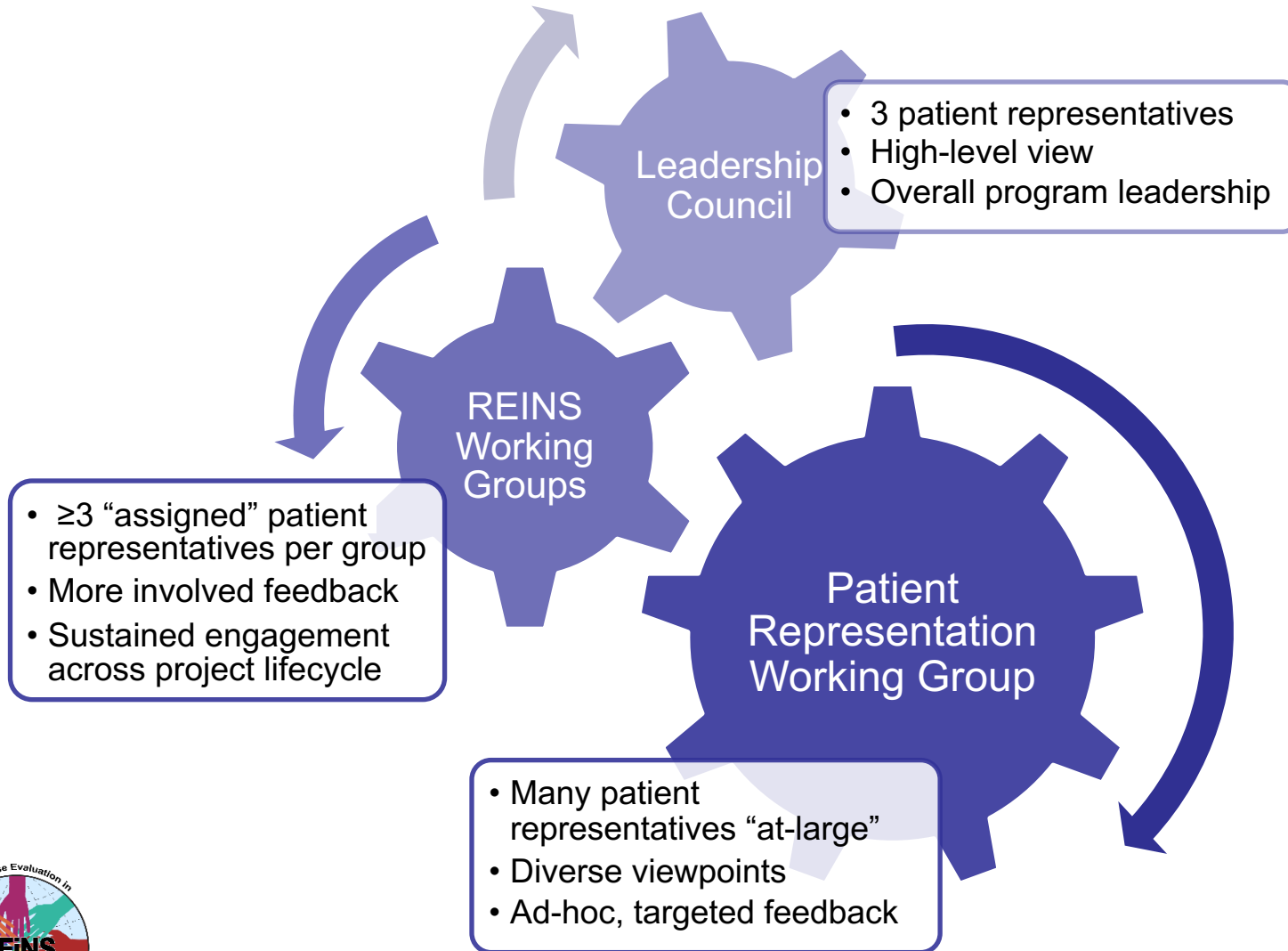


Expanding the Pool of Patient Representatives

- All patient representatives
 - Attend monthly PR working group meetings
 - Attend bi-annual meetings (virtually?)
- Patient representatives assigned to specific working groups
 - Matched to topical working groups based on personal interests & availability and group needs
 - Attend topic-specific working group meetings and review related materials



Patient Engagement in REiNS



Recruiting REiNS Patient Representatives 2.0

- Pre-recorded webinar
- Written job advertisement
- Live Q+A and/or buddy system
 - Ways for applicants to contact current patient representatives
- Targeted outreach through patient advocacy organizations, NF clinics, etc.
- Simplified online application



Next Steps

- Recruit new patient representatives
- Develop onboarding/educational materials
 - Update the website snapshots
 - Focus on adapting existing resources
- Addressing additional priority items
 - Best practices handbook
 - Improving technology for in-person meetings
 - Follow-up evaluation



Patient Representative Group

Alex Cellucci
Andrea Gross
Andres Lessing
Annette Bakker
Bev Oberlander
Brandie Evans
Cindy Hahn
Claas Rohl
Connie Sorman
Dale Berg
Dena Hasselberg
Diana Haberkamp
Gregg Erickson
Herb Sarnoff
Jessica Samblanet

Kallie Enman
Karen Peluso
Kim Bischoff
Krizelle Alcantara
Maureen Hussey
Onno Faber
Pam Knight
Pam Wolters
Renie Moss
Rosemary Anderson
Sarah Adsit
Scott Plotkin
Tammy Benson-O'Brian
Traceann Rose
Tracy Wirtnanen
Vanessa Merker

