

# Patient Engagement in REiNS: Benefits, Challenges, and Opportunities

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Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

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  - Barbara Franklin
  - Krista Frederick
  - Stephanie Reeves
- REiNS PRO group patient liaison:
  - Vanessa Merker



# Patient Engagement in Research

- Meaningful and active collaboration of patients and caregivers in the entire research process
  - Setting priorities for research topics
  - Selecting meaningful study outcomes
  - Reviewing study materials (recruitment flyers, instructions for procedures, informed consent documents)
  - Providing input on study design to make it more feasible
  - Helping to disseminate findings
- Researchers + patients/caregivers working **together** as a team



# Benefits of Patient Engagement

## For researchers:

- Different perspectives from patients may highlight issues not considered
- Identification of new research topics
- More feasible and relevant trial designs
- Meaningful and novel study outcomes
- Improved adherence to procedures
- Better recruitment and less attrition



# Benefits of Patient Engagement

## For patients and caregivers:

- Making research studies more relevant and feasible for patients/caregivers
- Creating positive outcomes from having a chronic illness like NF
- Feeling more empowered and self-confident from their contributions
- Forming new relationships and a sense of community



# Challenges to Patient Engagement

## For Researchers:

- Change is hard!
- Being open to ideas from patients and care partners
- Developing new models of care as equal partners
- Requiring increased resources
- Avoiding token or tokenism



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# Challenges to Patient Engagement

## For Patients:

- Adjust to a new role
- Unfamiliar terminology and procedures
- Increased time and effort
- Juggling competing jobs and family obligations
- Limited funds for travel and meetings



# Continuum of Patient Engagement



**Passive**

Patient is a data point






**Active**

Patient is a researcher





# Process of Patient Engagement

	<b>Inform &amp; Educate</b>	<b>Listen &amp; Gather</b>	<b>Discuss</b>	<b>Involve</b>	<b>Partner</b>
<b>Direction &amp; Strength of Engagement</b>	Researchers to Patients 	Patients to Researchers 	Bidirectional 	Bidirectional and Ongoing 	Joint Venture 
<b>Definition</b>	Patients benefit from information and education	Patients present their perspective	Patients provide valuable input and receive feedback	Patients are ongoing advisors	Patients are full participants
<b>Methods</b>	Websites, newsletters, webinars	Patient surveys, suggestions, perspectives	Focus groups, interactive interviews	Ongoing discussions in working groups and advisory boards	Voting members of leadership boards, active member of research teams

Adapted from Hahn et al., 2017



# Ways to Increase Patient Engagement in REiNS

- Provide education and training
- Integrate patients on all working groups
- Have patient liaisons for working groups
- Schedule regular calls at convenient times
- Work together to generate meaningful opportunities for engagement
- Listen and be open to new ideas
- Respect everyone's opinions



# Current Opportunities in REiNS

- Participate in monthly working group calls
- Attend in-person REiNS meetings
- Develop training plan and educational materials (glossary of terms, webinars, videos)
- Generate and implement fundraising suggestions
- Assist in developing patient surveys



# Current Opportunities in REiNS

- Review new outcome measures
- Share experiences when completing outcome measures
- Provide input on REiNS-related research protocols to develop new outcome tools
- Assist with meeting presentations – from slide preparation to giving talks
- Assist with writing/reviewing publications



# Summary

- Patient engagement is beneficial for meeting the goals of REiNS to standardize outcomes in NF clinical trials
- Change toward having active patient engagement is a process with challenges
- REiNS is committed to engage patients as partners in research
- Many opportunities are available for patient engagement in REiNS



# How to become involved in REiNS

- Interested in REiNS work?
  - Visit the REiNS website  
<https://ccrod.cancer.gov/confluence/display/REiNS/Home>
  - Attend open REiNS meetings
- Want to be a patient representative?
  - Application process every 2-3 years
  - Information circulated by NF Foundations and CTF Registry
  - For more information contact: Rachel Thalheimer at  
[rthalheimer@mgh.harvard.edu](mailto:rthalheimer@mgh.harvard.edu)



# REINS

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## Current Perspective from a Patient Representative

Maureen Hussey, May 2018



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# Current Perspective

*Patient Representative*

**Patient and caregiver input is essential to the process of developing recommended outcomes for clinical trials**

- Endpoints are more relevant to patient quality of life
- Leads to increased trial participation by patients





# Current Perspective

## *Becoming a Patient Representative*

- Invitations to apply Fall '17
  - Personal letter with skills and experience that lends to patient advocacy
  - Letter of reference
- Working groups assigned
  - Based on patient rep's experience with NF
- Invitation to attend REINS Winter meeting in D.C.
- Aren't these kids cute?!



Sometimes

# Current Perspective

## *Getting Started*

### First Collaborative Meeting – December '17

- Introduction to REINS
- Overview of the research process and clinical trials
- Descriptions of each working group and current goals
- First breakout with our working groups
- Brainstorming for funding and training
  - Monthly call with REINS leadership to collaborate



# Current Perspective

*Patient Representative*

## Neurocognitive Outcomes Working Group

Chair, Dr. Jennifer Janusz, Children's Hospital Colorado

- Reviewed common neurocognitive measures used by psychologists for patients and caregivers during testing
- Completed COGRATE for each measure
  - Cognitive Outcomes Rating Acceptance Tool for Endpoints
  - Rated tests on usability, understandability and relevance for NF1 patients
- Provided feedback on the working group's plans for their presentation today and goals for the breakout session



# THANK YOU!

