

# Incorporating Patient Representatives into REiNS

---

Scott Plotkin, MD, PhD  
Brigitte Widemann, MD

REiNS Winter Meeting  
December 4, 2017



Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

# What is REiNS?

## *Response Evaluation in NF and Schwannomatosis*

- The REiNS working group is an international effort to develop standardized response criteria for determining treatment response in patients



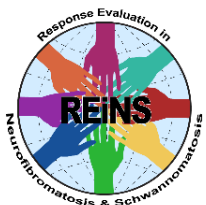
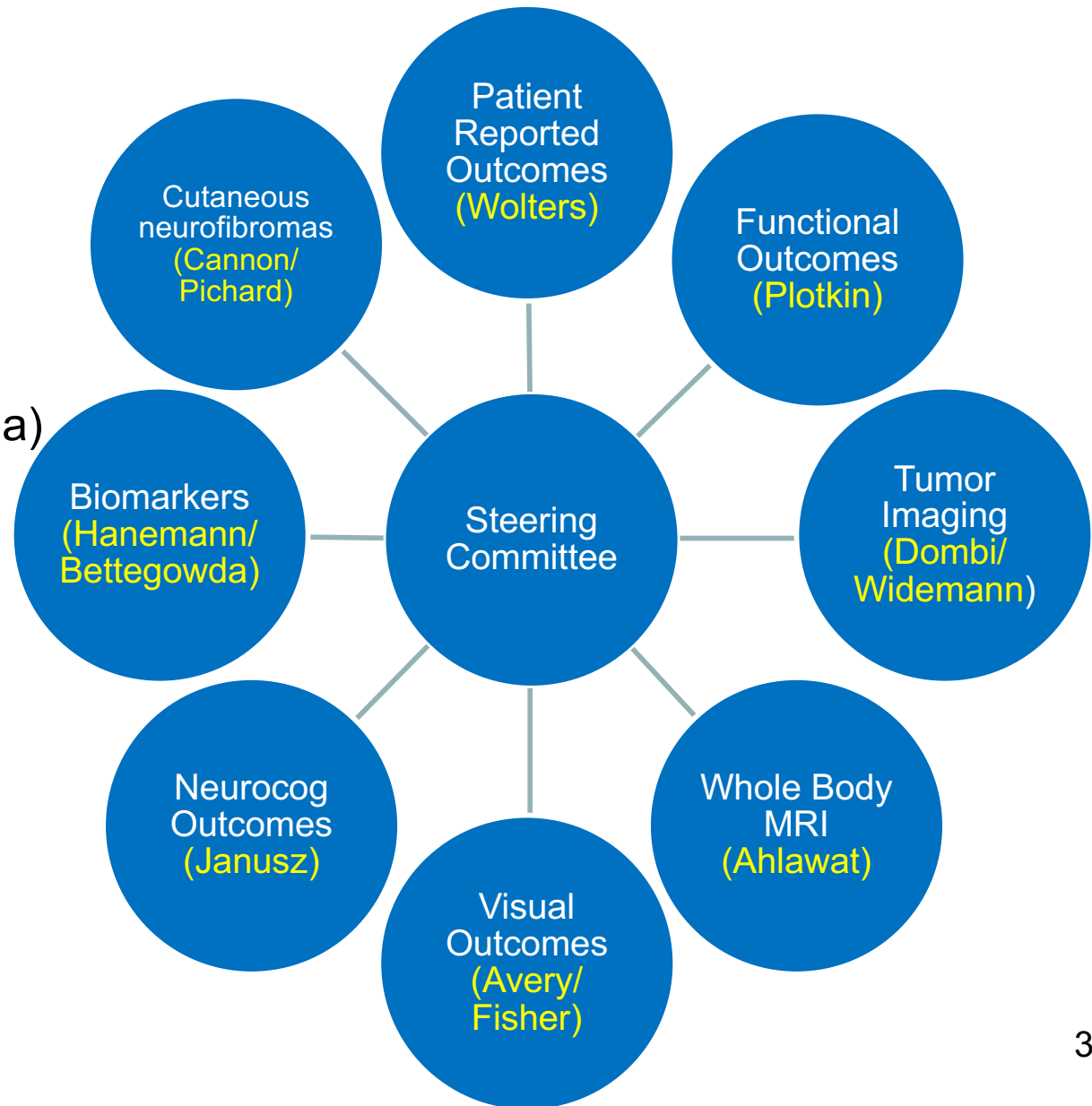
- 7 working groups
- >75 active members
- 30 patient representatives

*The REiNS working groups are open to all participants*

# REiNS Organizational Structure

## Steering Committee:

Brigitte Widemann (NCI)  
Scott Plotkin (MGH)  
Jaishri Blakeley (Hopkins)  
Eva Dombi (NCI)  
Oliver Hanemann (Peninsula)  
Karin Walsh (CNMC)  
Pam Wolters (NCI)



# REiNS publications 2013

Neurology® Sept 2013

Volume 81 Number 21 November 19, 2013 Supplement 1

## Neurology®

Volume 81, Number 21, Supplement 1, November 19, 2013  
Neurology.org

AMERICAN ACADEMY OF  
NEUROLOGY.

### Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS)

Guest Editors: Scott R. Plotkin, MD, and Brigitte C. Widemann, MD

Supplement to *Neurology*®



1. Achieving consensus for clinical trials: The REiNS International Collaboration
2. Patient-reported outcomes in neurofibromatosis and schwannomatosis clinical trials
3. Functional outcome measures for NF1-associated optic pathway glioma clinical trials
4. Hearing and facial function outcomes for neurofibromatosis-2 clinical trials
5. Recommendations for imaging tumor response in neurofibromatosis clinical trials
6. Conclusions and future directions for the REiNS International Collaboration

CHILDREN'S  
TUMOR  
FOUNDATION  
ENDING NF  
THROUGH RESEARCH

# REiNS publications 2016

Neurology® Suppl 1

Volume 81 Number 21 November 19, 2013 Supplement 1

## Neurology®

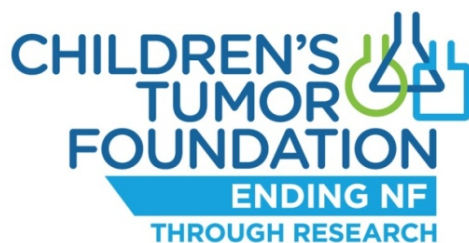
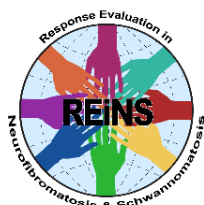
Volume 81, Number 21, Supplement 1, November 19, 2013  
Neurology.org



### Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS)

Guest Editors: Scott R. Plotkin, MD, and Brigitte C. Widemann, MD

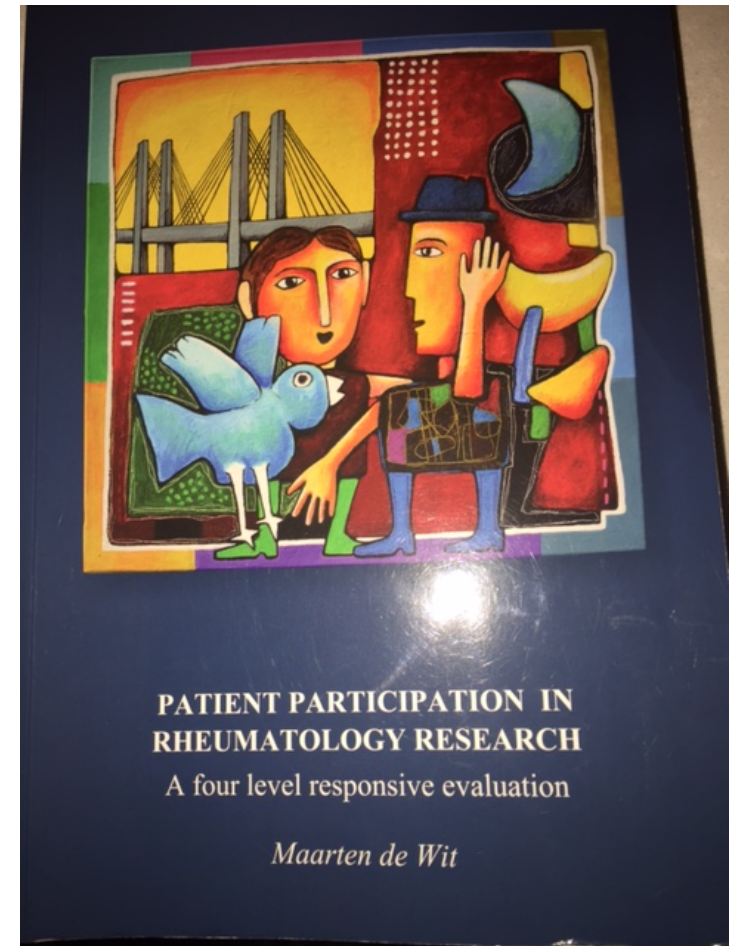
Supplement to *Neurology*®



- 1. Widemann BC, Plotkin SR. Consensus for NF clinical trials: Recommendations of the REiNS collaboration (Supplement II). *Neurology* 2016 Aug 16;87(7 Suppl 1):S1-S3. [\[PDF\]](#)
- 2. Wolters PL, Martin S, Merker VL, et al. Patient-reported outcomes of pain and physical functioning in neurofibromatosis clinical trials. *Neurology* 2016 Aug 16;87(7 Suppl 1):S4-S12. [\[PDF\]](#)
- 3. Plotkin SR, Davis SD, Robertson KA, et al. Sleep and pulmonary outcomes for clinical trials of airway plexiform neurofibromas in NF1. *Neurology* 2016 Aug 16;87(7 Suppl 1):S13-20. [\[PDF\]](#)
- 4. Walsh KS, Janusz J, Wolters PL, et al. Neurocognitive outcomes in neurofibromatosis clinical trials: Recommendations for the domain of attention. *Neurology* 2016 Aug 16;87(7 Suppl 1): S21-30. [\[PDF\]](#)
- 5. Ahlawat S, Fayad LM, Khan MS, et al. Current whole-body MRI applications in the neurofibromatoses: NF1, NF2, and schwannomatosis. *Neurology* 2016 Aug 16;87(7 Suppl 1): S31-9. [\[PDF\]](#)
- 6. Hanemann CO, Blakeley JO, Nunes FP, et al. Current status and recommendations for biomarkers and biobanking in neurofibromatosis. *Neurology* 2016 Aug 16;87(7 Suppl 1): S40-8. [\[PDF\]](#)

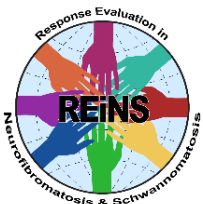
# 2016 Winter Meeting

- Aims:
  - To educate neurofibromatosis researchers and clinicians about the utility of increased patient engagement in developing endpoints for clinical trials.
  - To engage patients, family members, and other stakeholders in the NF community in the REiNS collaboration.
  - To generate a roadmap for developing patient engagement guidelines in REiNS subgroups.



# 2017 Winter Meeting

- Aims:
  - To train NF researchers and clinicians how to engage constructively with patient representatives within REiNS working groups
  - To train patient representatives how to work effectively within REiNS working groups
  - To update the NF community about ongoing efforts within the REiNS working groups



- 8:00 – 8:30 am Breakfast
- 8:15 am Welcome and introduction  
Scott Plotkin (MGH) and Brigitte Widemann (NCI)
- 8:30 – 9:15 am Patient-Centered Outcomes Research Institute: Mission  
and Funding Opportunities  
Parag Aggarwal, PhD
- 9:15 – 9:45 am FDA perspective on patient engagement  
Steve Morin, RN, BSN (FDA)
- 9:45 – 10:00 am Recruiting patient representatives to REiNS: Initial Results  
Scott Plotkin
- 10:00 – 10:30 am Training NF researchers to work with patient representatives  
Vanessa Merker
- 10:30 – 11:00 am Break



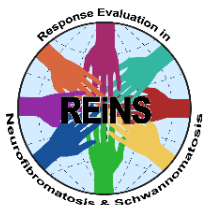


- 11:00 – 11:30 am Training patient representatives to work with NF researchers  
Claas Röhl
- 11:30 – 12:00 pm CTF Patient Engagement Initiative  
Traceann Rose (Children’s Tumor Foundation)
- 12:00 – 1:30 pm Patient representative introduction  
Lunch at local venues
- 1:30 – 3:00 pm Working group presentations (7 minutes each)  
REiNS Members
- 3:00 – 5:00 pm Working group meetings including NF researchers and Patient Representatives
- 5:00 – 5:30 pm Informal working group reports
- 5:30 – 6:00 pm Networking and informal discussions



# Working group sessions

	3 – 4 pm	4 – 5 pm
Area 1	PRO	PRO
Area 2	Functional	Biomarkers
Area 3	Tumor Imaging	WBMRI
Area 4	Neurocognitive	Neurocognitive
Area 5	Cutaneous NF	Cutaneous NF



# Acknowledgements



Vanessa Merker

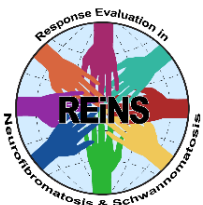


Anna Maria Benigni

Elise Mongeon (ASL interpreter)

Lisette Madalena (ASL interpreter)

NCI grant R13 TR002095-02 (NCATS)  
Children's Tumor Foundation



# Social Media

- Twitter: @REiNScollab

**REiNS Winter 2017 Meeting**  
Mon, Dec 4, 2017 7:45 AM - 3:45 PM EST

**Please join my meeting from your computer, tablet or smartphone.**

<https://global.gotomeeting.com/join/451021245>

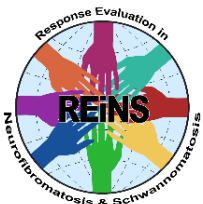
**You can also dial in using your phone.**

United States: +1 (786) 535-3219

**Access Code: 451-021-245**

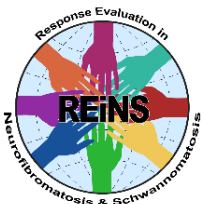
**More phone numbers**

United Kingdom: +44 20 3713 5028



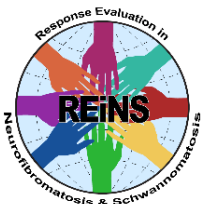
# Future directions

- November 2018 meeting in Paris, France
- Continued development of outcomes measures in each working group
- New working group
  - Patient representation
- REiNS Website  
(<https://ccrod.cancer.gov/confluence/display/REiNS/>)
- Apply for funding through PCORI to support patient engagement



# Feedback

- Please fill out evaluation forms to help improve REiNS winter meeting
  - Needed for R13 competitive renewal in 2/2018



# Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS)

- Imaging response (Widemann, Dombi)
- Functional outcomes (Plotkin)
- Patient reported outcomes (Wolters)
- Whole body MRI (Ahlawat)
- Visual outcomes (Fisher)
- Neurocognitive outcomes (Walsh)
- Biomarkers (Hanemann)

***The REiNS working groups are open to all participants***



- 7 working groups
- >75 active members

