

Paris 2018

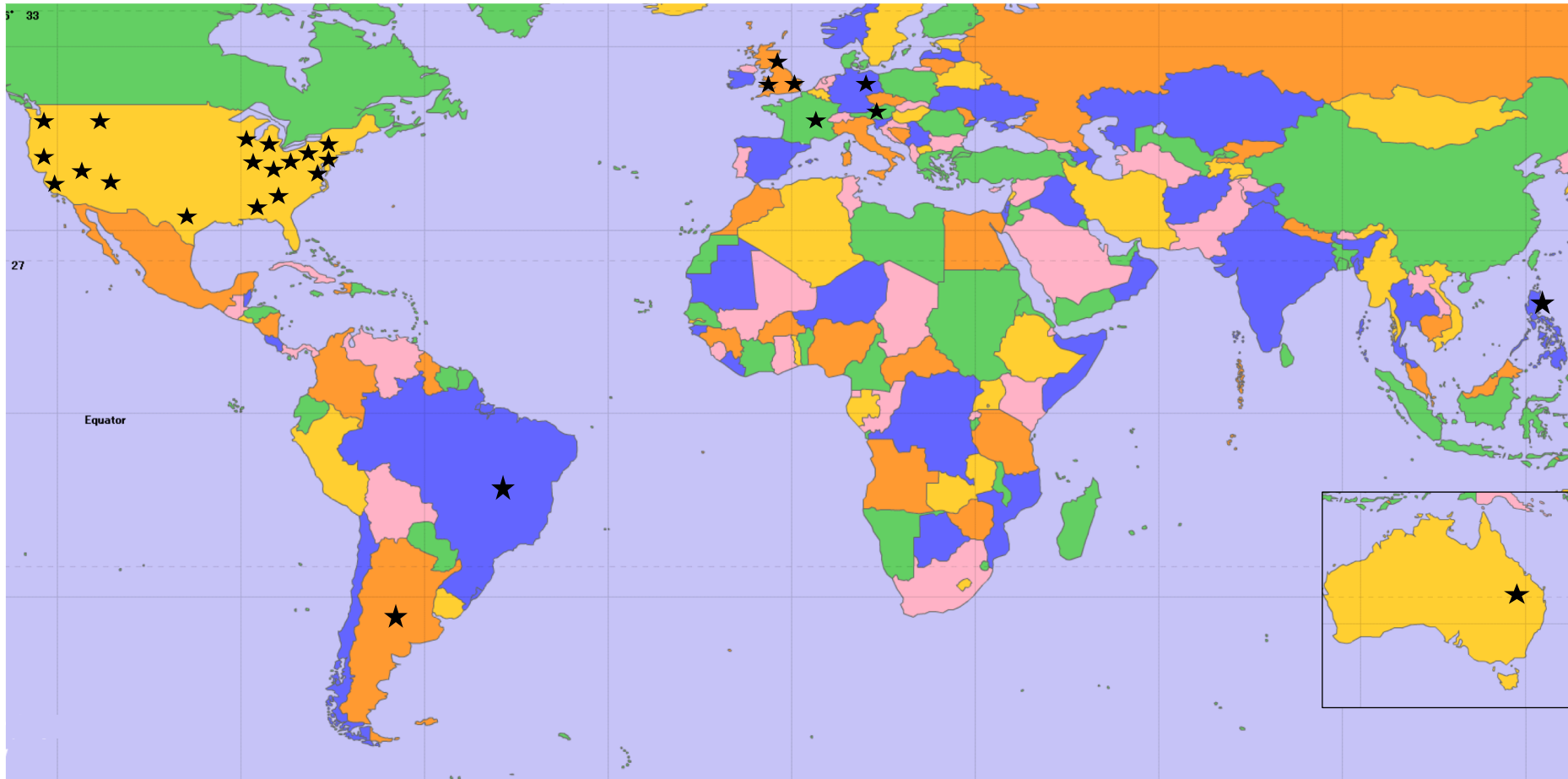
“Summer” REiNS meeting

Scott Plotkin, MD, PhD
Brigitte Widemann, MD



Response Evaluation In Neurofibromatosis Schwannomatosis
INTERNATIONAL COLLABORATION

Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) Collaboration

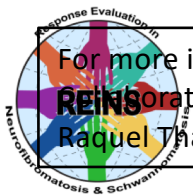


**Please join us for our REiNS session November 6th
3pm-6pm**

<https://ccrod.cancer.gov/confluence/display/REiNS/Home>

Working groups and leaders:

- Tumor Imaging/Whole Body MRI (Eva Dombi, Shivani Ahlawat)
- Functional outcomes (Scott Plotkin)
- Patient reported outcomes (Pam Wolters)
- Visual outcomes (Rob Avery, Michael Fisher)
- Disease Biomarkers (Chetan Bettgowda, Oliver Hanemann)
- Neurocognitive outcomes (Jennifer Janusz)
- Cutaneous neurofibromas (Ashley Cannon, Dominique Pichard)
- Patient Representation (Scott Plotkin, Andrea Gross)



For more information about the REiNS International Collaboration and working groups, please contact Raquel Thalheimer, rthalheimer@mgh.harvard.edu

REiNS Publications:

Supplement 1 (Neurology 2013, Volume 81, Issue 21)

1. Plotkin SR, Blakeley JO, Dombi E, et al. Achieving consensus for clinical trials: the REiNS International Collaboration.
2. Wolters PL, Martin S, Merker VL, et al. Patient-reported outcomes in neurofibromatosis and schwannomatosis clinical trials.
3. Fisher MJ, Avery RA, Allen JC, et al. Functional outcome measures for NF1-associated optic pathway glioma clinical trials.
4. Plotkin SR, Ardern-Holmes SL, Barker FG, et al. Hearing and facial function outcomes for neurofibromatosis 2 clinical trials.
5. Dombi E, Ardern-Holmes SL, Babovic-Vuksanovic D, et al. Recommendations for imaging tumor response in neurofibromatosis clinical trials.
6. Widemann BC, Blakeley JO, Dombi E, et al. Conclusions and future directions for the REiNS International Collaboration.

Supplement 2 (Neurology 2016, Volume 82, Issue 7)

1. Widemann BC, Plotkin SR. Consensus for NF clinical trials: Recommendations of the REiNS collaboration (Supplement II).
2. Wolters PL, Martin S, Merker VL, et al. Patient-reported outcomes of pain and physical functioning in neurofibromatosis clinical trials.
3. Plotkin SR, Davis SD, Robertson KA, et al. Sleep and pulmonary outcomes for clinical trials of airway plexiform neurofibromas in NF1.
4. Walsh KS, Janusz J, Wolters PL, et al. Neurocognitive outcomes in neurofibromatosis clinical trials: Recommendations for the domain of attention.
5. Ahlawat S, Fayad LM, Khan MS, et al. Current whole-body MRI applications in the neurofibromatoses: NF1, NF2, and schwannomatosis.
6. Hanemann CO, Blakeley JO, Nunes FP, et al. Current status and recommendations for biomarkers and biobanking in neurofibromatosis.

- 3:00 – 3:10 pm Welcome and leadership update
Scott Plotkin and Brigitte Widemann
- 3:10 – 5:55 pm REiNS working groups updates (with feedback from attendees)
- 3:10– 3:35 Reliability of functional outcome measures in NF1
Rosalie Ferner, MD, (Guy and St. Thomas') for the Functional Endpoints Working group
- 3:35– 4:00 Hand held dynamometry for strength measurement
Srivandana Akshintala, MD, (NYU) for the Functional Endpoints Working group
- 4:00 – 4:25 Patient reported outcomes for trials of cutaneous neurofibroma: measuring itch, pain, and visibility
Chris Moertel, MD (U. Minnesota) for the Cutaneous Neurofibroma Working group
- 4:25 – 4:50 Translating patient views about cNFs into severity scales
Ashley Cannon, PhD (UAB) and Dominique Pichard, MD (NIAMS) for the Cutaneous Neurofibroma Working Group
- 4:50 – 5:10 Educational programming for patient representatives
Claas Rohl and Andrea Gross, MD (NCI) for the Patient Representation Working Group
- 5:10 – 5:35 Social cognition outcome measures
Jennifer Janusz, PhD (Children's Hospital Colorado) for the Neurocognitive Working Group
- 5:35 – 6:00 General quality of life and disease-specific QOL
Pam Wolters, PhD (NCI) for the PRO Working Group



Leadership changes

- The Steering Committee for REiNS has approved a new leadership structure that will take effect on January 1, 2019. The goal of this change is to broaden the leadership structure to include a wider array of voices and opinions.
- The **Directors Council** will include approximately 20 members who currently serve in leadership roles – often as leaders of working groups or Winter meeting. The Directors Council will meet monthly to provide working group updates to discuss annual meetings in June and December.
- There will also be an **Advisory Council** composed of about 5 members that would be responsible for planning to overall course of the REiNS Collaboration. This team would think strategically about opportunities over the next 1-5 years that will keep our Collaboration relevant and further our engagement with the FDA, NIH, and industry



Acknowledgements



Raquel Thalheimer

