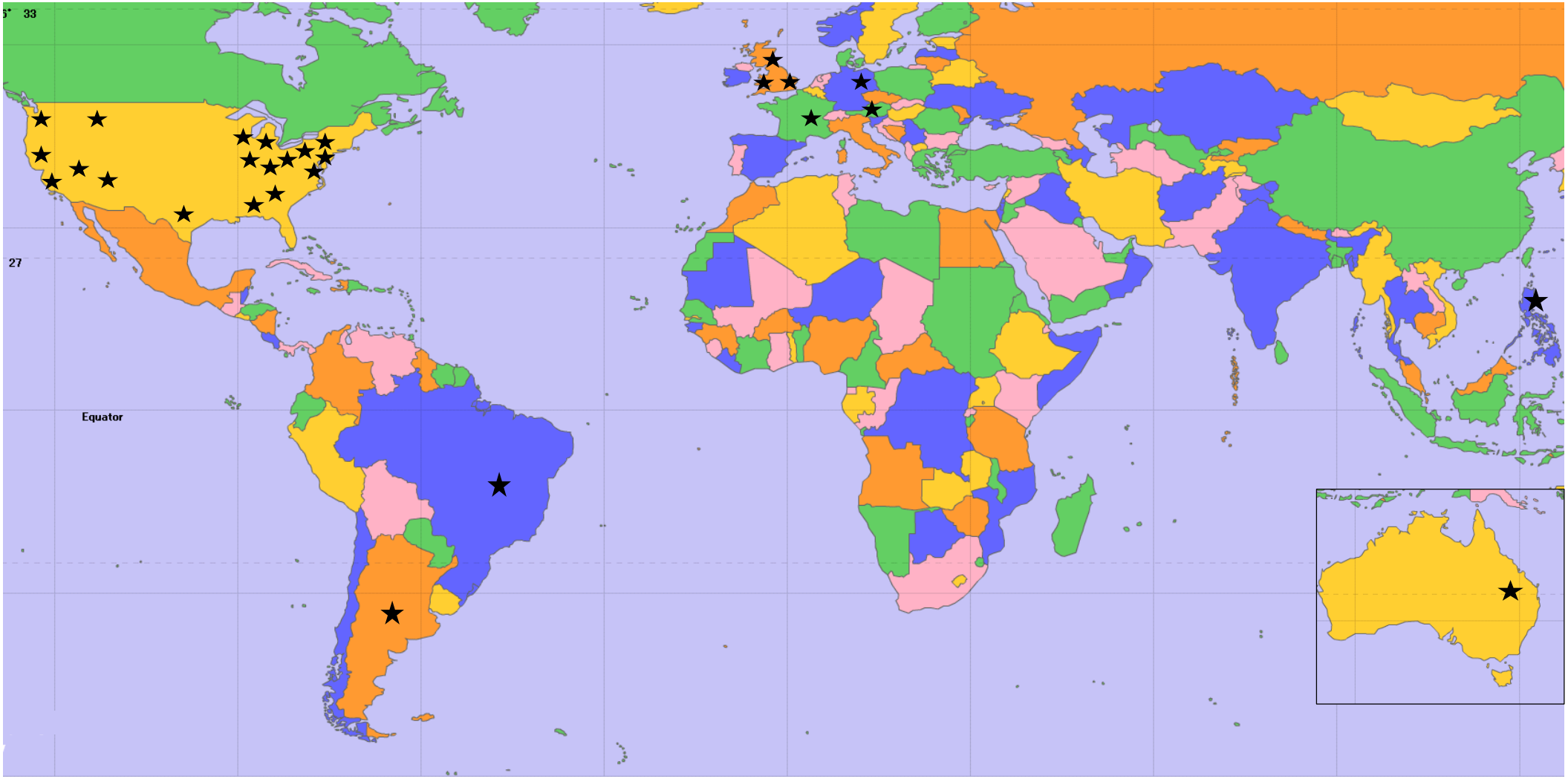
Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS)



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

https://ccrod.cancer.gov/confluence/display/REINS/Home

Meeting Details

Open to all attendees of the CTF meeting (including patient representatives)

Place: Maison de la Chimie
Room: Room 101

Goals:
1.To update REiNS member about ongoing activities in select working group (patient-reported outcomes, cutaneous neurofibroma, neurocognitive, functional, and patient representation)

Agenda:

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) 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*
6:00 pm	Conclusion and Future Plans for REiNS *Scott Plotkin, MD, PhD (MGH) and Brigitte Widemann, MD (NCI)*

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 Bettegowda, Oliver Hanemann)
- Neurocognitive outcomes (Jennifer Janusz)
- Cutaneous neurofibromas (Ashley Cannon, Dominique Pichard)
- Patient Representation (Scott Plotkin)

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.