

Presentations

General

[REINS International Collaboration Poster](#)

[REINS Patient Centered Research Poster](#)

[REINS Patient Engagement - December 2016](#)

[REINS Patient Engagement Teleconference - November 20th, 2017](#)

Working Groups

[REINS Patient Reported Outcome Measures Poster](#)

[REINS Functional Outcomes Measures Poster](#)

[REINS Neurocognitive Outcome Measures Poster](#)

[PN: Volume Segmentation](#)

[PN3: Volume Segmentation Neck Chest Date 1](#)

[PN3: Volume Segmentation Neck Chest Date 2](#)

[PN3: Volume Segmentation Neck-Chest Date 3](#)

REiNS Meetings

December 2023 Winter Meeting (Baltimore, MD)

- [1. REiNS 2023 Winter Meeting Welcome and Introduction](#)
- [2. Understanding decentralized trials: benefits and challenges](#)
- [3. Inching towards decentralized trials for NF1 and SWN](#)
- [4. FDA Guidance on Decentralized Clinical Trials](#)
- [5. Digital Biomarkers to support decentralized trials](#)
- [6. Assessing functional endpoints for NF1 and SWN in decentralized trials](#)
- [7. Visual Outcomes in Decentralized Trials](#)
- [8. Imaging Working Group Update: Imaging Outcomes in Decentralized Clinical Trials](#)
- [9. Assessing cutaneous neurofibromas in decentralized trials](#)
- [10. Assessing Patient-Reported Outcomes \(PROs\) in Decentralized Trials](#)
- [11. Decentralized Neurocognitive Trials](#)
- [12. Biomarkers in decentralized trials](#)

June 2023 Summer Meeting (Scottsdale, AZ)

- [1. REiNS 2023 Summer Meeting Welcome and Introduction](#)
- [2. Perspectives of Adolescents with NF1 and Cutaneous Neurofibromas](#)
- [3. A core outcome domain set to assess cutaneous neurofibromas related to neurofibromatosis type 1 in clinical trials](#)
- [4. REiNS Patient Representative Membership and Activities](#)
- [5. Updates from the PRO Working Group: An Evaluation of Measures Used to Assess Anxiety and Depression for Individuals with Neurofibromatosis and Schwannomatosis](#)
- [6. Neurocognitive Outcomes Working Group Update: Evaluation of Measures of Intellectual Ability, Memory, Language and Executive Functions](#)

7. Gene-Targeted Therapies Working Group: Patient preference studies for gene-targeted therapy
8. REiNS Functional Group Update
9. Opportunities to Engage with FDA
10. Prospective Evaluation of Skeletal Disease Manifestations in NF1

December 2022 Winter Meeting (Baltimore, MD)

1. Summarizing key regulatory issues of interest for REiNS
2. What is Required for Drug Approvals in Common and Rare Diseases and How Natural History Studies Can Help
3. FDA Perspective: Approach to Rare Diseases and Use of Natural History Studies
4. Support for developing medicines to address unmet medical needs of patients with a rare disease
5. Regulatory Approval of Selumetinib for NF1 Plexiform Neurofibromas: How Did We Get There & Lessons Learned
6. The natural history of Neurofibromatosis Type 2: National Institutes of Health Cohort
7. Natural History of Schwannomatosis-Related Pain
8. Natural History Study of Cutaneous Neurofibromas In People With NF1
9. International Multi-Center Natural History Study of Newly Diagnosed NF1-Associated Non-Optic Pathway Glioma

June 2022 Summer Meeting (Philadelphia, PA)

1. Neurocognitive Outcomes Working Group Update
2. REiNS Functional Group Update
3. Imaging Working Group Update
4. Biomarker Group Update
5. REiNS Mini-symposium: Consensus meeting to define the minimal set of outcomes to be reported for clinical trials of cutaneous neurofibromas

Virtual Winter Meeting - March 2022

Patient Representative Meeting

1. Understanding the Genetic Code and Successful/Unsuccessful Approaches to Gene Directed Therapies
2. A (Very Brief) History of Gene Directed Therapy Trials for Humans

General Meeting

3. Welcome Slides
4. Facilitating the Development of Gene Therapy for Conditions that are Less Common
5. Gene Therapy Approaches for the Leukodystrophies
6. Scientific Approaches to Gene Directed Therapies for NF2 and Schwannomatosis
7. Safety Issues of Gene Therapy
8. An Ethical Framework for Initiating Human Trials of Gene Directed Therapies in NF: Deciding When? Who? How?
9. Gene Directed Therapies: Interactive Exercise

Virtual Summer Meeting - June 2021

1. Welcome Slides
2. Developing Endpoints Across Multiple Cognitive Domains
3. Update from the Patient Reported Outcomes Working Group

4. REiNS Patient Representative Group Update
5. REiNS Functional Group Update
6. Identifying Clinical, Genetic, and Radiologic Features Associated with Increased Risk for MPNST

Virtual Winter Meeting - March 2021

1. Developing skeletal outcomes for NF Clinical Trials: Welcome and Direction
2. Techniques and Endpoints for Osteoporosis in NF1
3. Longitudinal Evaluation of Bone Density in Children & Young Adults with Neurofibromatosis Type 1
4. Endpoints for Study of Scoliosis
5. Radiation Risks of Imaging Studies
6. Application of X-ray, MRI, pQCT, and DXA in a Natural History Study of Scoliosis Progression in Children with NF1
7. Getting Ahead of the Curve: MRI vs. Radiographs for NF1 Related Scoliosis
8. Dystrophic Scoliosis and NF1: Parent Perspective
9. Patient reported outcomes for NF1-related Scoliosis: domains of interest

Virtual Summer Meeting - June 2020

1. Introduction and REiNS Updates.
2. Taking the REiNS: FDA Approval of Selumetinib for NF1
3. Developing Endpoints for Skeletal Manifestations of NF1
4. Developing Endpoints Across Multiple Cognitive Domains
5. Assessing Perceived Disfigurement in NF Clinical Trials
6. Recruiting Patient Representatives to REiNS: Version 2.0.

REiNS Winter Meeting - December 2019 (Baltimore, MD)

1. REiNS Functional and PRO Recommendations Applied in NF1 Trials: From Theory to Practice
2. Evaluating the Impact of REiNS on Clinical Trials for NF2 and SWN: 2011 - 2019
3. Clinical Trial Design for Cutaneous Neurofibromas
4. Review of Proposed Outcome Measures for cNF: Tumor Size, PROs, and Global Assessment of Change (GAC)
5. Selumetinib Trial Targeting Cutaneous Neurofibromas: Preliminary Findings and Lessons Learned
6. Proposed Design for an Activity Finding Trial Using Local Therapy
7. Proposed Design for Activity-Finding Trial Using Systemic Therapy for cNF
8. Assessing the Strengths and Weaknesses of the REiNS Patient Representative Program

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September 2019 CTF Conference REiNS Session (San Francisco, CA)

1. Reliability of measuring muscle strength using a hand-held dynamometer in NF .pdf
2. Assessing Established PROs for cNFs: Are these Scales Adequate for Clinical Trials?
3. Using Patient Views to Inform the Design of Clinical Trials for cNF
4. Evaluating the REiNS Patient Representative Program
5. REiNS Neurocognitive Update - Preschool Subcommittee and Broader Committee
6. REiNS Patient Reported Outcomes (PRO) Working Group

December 2018 Winter Meeting (Bethesda, MD)

1. Incorporating Biomarkers into Cutaneous Neurofibroma Trials
2. A Regulatory Perspective on Novel Efficacy Endpoints
3. Designing Clinical Trials for Cutaneous Neurofibromas, an Unmet Need for Patients with NF1
4. Measuring Change in Cutaneous Neurofibroma Size - Novel Techniques and Endpoints
5. The Path Traveled: Progress in Developing Therapeutics for Cutaneous Neurofibromas
6. What Constitutes Clinical Benefit for Trials of cNF?
7. Patient Reported Outcomes for Trials of Cutaneous Neurofibromas
8. Ongoing Studies of Cutaneous Neurofibromas: Trial Design and Endpoints
9. Results of a Survey of NF1 Patients Defining Symptom Burden of Cutaneous Neurofibromas
10. REiNS Survey Results

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November 2018 CTF Conference REiNS Session (Paris, France)

1. Introduction to 2018 Summer REiNS Meeting - Paris
2. Social Cognition Outcomes Measures
3. Patient Reported Outcomes (PRO) Working Group
4. Combined Whole Body MRI and Tumor Imaging
5. Patient Representative Training
6. Functional Motor Outcome Measures in Adults with NF1
7. Statistical Validation of Skindex Between Two Institutions
8. Translating Patient Views into Global Assessments

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May 2018 NF Forum REiNS Session (Atlanta, GA)

1. Patient Engagement in REiNS: Benefits, Challenges, and Opportunities
2. REiNS Patient Representative Training
3. Functional Measurements in Clinical Trials for Plexiform Neurofibromas
4. REiNS Neurocognitive Committee
5. Cutaneous Neurofibromas

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December 2017 REiNS Working Group Updates (Bethesda, MD)

1. REiNS Functional Group
2. REiNS PRO
3. REiNS Tumor Imaging Group
4. REiNS WBMRI Group
5. REiNS Visual Outcomes Group
6. REiNS Neurocognitive Group
7. REiNS Biomarkers Group
8. REiNS cNF Group

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December 2017

Invited Speakers

1. REiNS Introduction
2. REiNS PCORI
3. REiNS Patient Representation
4. REiNS Training Researchers
5. REiNS Teaching Patient Reps
6. REiNS Patient Engagement

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June 2017

1. REiNS Roadmap for Patient Engagement
2. REiNS Strength Testing in NF
3. REiNS cNF Working Group Update
4. REiNS Preschool Neurocog Update
5. REiNS General QOL Update

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December 2016

1. REiNS Patient Priorities
2. REiNS Enhancing Patient Engagement
3. REiNS Patient Engagement
4. REiNS Developing PROS using patient focus groups

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