

# The Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS)

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## Research Areas



### Tool Development

Clinical Trial



### Biomarker Research

Drug



### Basic Research



### Product Development

Data

## At a Glance

- Status: **Active Consortium**
- Year Launched: **2011**
- Initiating Organization: **Children's Tumor Foundation**
- Initiator Type: **Nonprofit foundation**
- Location: **International**

## Abstract

The Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) International Collaboration was established in 2011 at the Children's Tumor Foundation meeting to achieve consensus within the NF community about the design of future clinical trials, with a specific emphasis on endpoints. The REiNS Collaboration includes 7 working groups that focus on imaging of tumor response; functional, visual, patient-reported, and neurocognitive outcomes; whole-body MRI; and disease biomarkers.

## Mission

The Response Evaluation in Neurofibromatosis and Schwannomatosis (REiNS) International Collaboration was established with the goal to develop consensus recommendations for the use of endpoints in neurofibromatosis (NF) clinical trials. This supplement includes the first series of REiNS

recommendations for the use of patient-reported, functional, and visual outcomes, and for the evaluation of imaging response in NF clinical trials.

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## Consortium History

The REiNS Collaboration was established in 2011 at the Children’s Tumor Foundation annual NF Conference to achieve consensus within the NF community about future clinical trials and to accelerate the identification of agents which will benefit individuals with NF. Since its inception, the REiNS International Collaboration has played a key role in the creation and dissemination of outcome measures for clinical trials of neurofibromatosis and schwannomatosis.

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## Structure & Governance

The REiNS collaboration is organized around eight working groups that focus on the following topics: imaging of tumor response, functional outcomes, visual outcomes, patient-reported outcomes, neurocognitive outcomes, whole-body MRI, disease biomarkers, and cutaneous neurofibromas. Leaders of the eight working groups were identified based on their expertise. Membership in each working group is open to any interested party and representatives from patient advocacy groups and funding agencies have been invited to participate in the effort.

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## Financing

Support is provided by a National Cancer Institute grant, “Developing endpoints to facilitate clinical trials in rare diseases,” and the Children’s Tumor Foundation.

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## Impact/Accomplishment

For a list of REiNS publications, click [here](#)

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## Links/Social Media Feed

Homepage	<a href="https://ccrod.cancer.gov/confluence/display/REINS/Home">https://ccrod.cancer.gov/confluence/display/REINS/Home</a>
Twitter	@reinscollab

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## Points of Contact

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## Sponsors & Partners

Children's Tumor Foundation  
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