

# Cutaneous Neurofibroma Working Group

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Ashley Cannon, PhD, MS, CGC

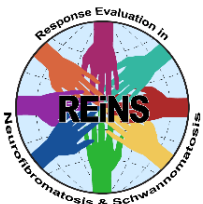
Dominique Pichard, MD



Response Evaluation In Neurofibromatosis Schwannomatosis  
INTERNATIONAL COLLABORATION

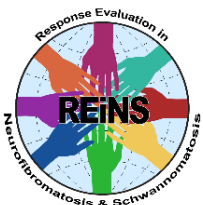
# Initial cNF Working Group Goals

- Identify working group members
- Establish monthly group meetings
- Develop project ideas



# cNF Working Group Members

- Dermatology
  - Dominique Pichard, NIH
  - Pierre Wolkenstein, Henri-Mondor Hospital
  - Lu Le, UTSW
  - Sheilagh Maguiness, UMN
  - Kavita Sarin, Stanford
  - Dawn Siegel, MCW
  - Ed Cowen, NIH
- Neurology
  - Kaleb Yohay, NYU
  - Victor-Felix Mautner, University Medical Center Hamburg-Eppendorf, Germany
  - Shannon Langmead, JHU
  - Tena Rosser, CHLA
- R&D
  - Sharad Verma, NTAP
- Genetics
  - Ashley Cannon, UAB
  - Betty Schorry, CCHMC
- Neuro-oncology
  - Michael Fisher, CHOP
  - Scott Plotkin, MGH
  - Chie-Schin Shih, Riley Children's
  - Jaishri Blakeley, JHU
  - Maciej Mrugala, Mayo
- Neuropathology
  - Anat Stemmer-Rachamimov
- Pediatric Oncology
  - Chris Moertel, UMN
  - Kathy Sommer, UMN
  - Pavlina Sverak, UMN
  - Brigitte Widemann, NIH
  - Andrea Baldwin, NIH
- Basic Sciences
  - Bob Kesterson, UAB
  - Deeann Wallis, UAB
- **Patient Representatives**
  - **Gregg Erickson**
  - **Claas Rohl**
  - **Sarah Adsit**



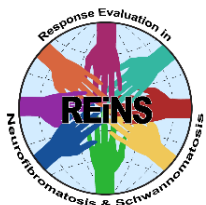
# Monthly group meetings

- Every 3<sup>rd</sup> Monday at 12:00pm EST
- Next: December 18<sup>th</sup>



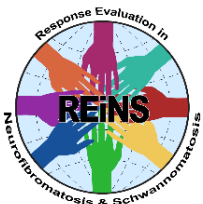
# cNF Working Group Goals

- Goals of the cNF working group to include:
  - 1) Identification of research priorities for cutaneous neurofibromas
  - 2) The development of recommendations for
    - clinical trial endpoints
    - clinical trial designs
    - outcome measures for clinical trials



# Project Ideas

- **Validate Skindex QOL Survey**
  - Led by Chris Moertel
  - In collaboration with PRO working group
- **Pruritus PRO**
  - In collaboration with PRO and biomarker working groups
- **Efficacious cNF burden PRO**
  - In collaboration with PRO working group
- **App for monitoring cNFs**
  - Similar to MoleMapper™ developed by Sage Bionetworks and OHSU



# Contact Information

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- Dominique Pichard:  
[dominique.pichard@nih.gov](mailto:dominique.pichard@nih.gov)

<https://ccrod.cancer.gov/confluence/display/REINS/Cutaneous+Neurofibromas>

