

REiNS Snapshot: Biomarker Group

Updated: March 12, 2019

Mission Statement

Clinically validated biomarkers for neurofibromatosis 1 (NF1), neurofibromatosis 2 (NF2), and schwannomatosis (SWN) have not been identified to date. The biomarker group concentrates on reviewing biomarkers in blood, urine, and tissue. Imaging biomarkers are discussed separately by the REiNS imaging working group).

Group Focus Areas:

- 1. Define biomarker needs in NF1, NF2, and SWN
- 2. Summarize existing data on biomarkers
- 3. Outline recommendations for sample collection and biomarker development
- 4. Standardize sample collection and methodology protocols where possible to promote comparison between studies by publishing standard operating procedures (SOPs)

Current Members

Researchers & Clinicians (Institution/email)	Patient Representatives (Organization/email)
C Oliver Hanemann, University of	Herb Sarnoff, Infixionbio
Plymouth,	
Chetan Bettagowda, Johns Hopkins	
University	
D Gareth Evans, Univesity of Manchester	
Meena Upadahyaya, Cardiff University,	
Aerung Kim, Children's National Medical Center	

Endpoints Published (.pdf reference):

Current status and recommendations for biomarkers and biobanking in
neurofibromatosis. Hanemann CO, Blakeley JO, Nunes FP, Robertson K, Stemmer-
Rachamimov A, Mautner V, Kurtz A, Ferguson M, Widemann BC, Evans DG, Ferner R,
Carroll SL, Korf B, Wolkenstein P, Knight P, Plotkin SR; REiNS International Collaboration
Neurology. 2016 Aug 16;87(7 Suppl 1):S40-8. doi: 10

C.

D.

Endpoints Being Evaluated (Project lead):

- A. Genotype-Phenotype correlations in neurofibromatosis and their potential clinical use
- В.
- C.
- D.



Meeting Schedule (Coordinator's contact info) 2019, contact Oliver.Hanemann@plymouth.ac.uk:

11 February 2019

4 June 2019

16 July 2019

1 October 2019