

Request for Applications: Clinical <u>Genomics</u> of <u>MPNST</u> (GeM) Consortium

Application Deadline: July 10th, 2017

Vision of the NF Research Initiative: Within the next 5 years, therapeutic development for NF1-related Malignant Peripheral Nerve Sheath Tumors (MPNSTs) will be transformed through international collaboration to improve the biological understanding of tumor progression in this disorder.

Goal of the Genomics of MPNST (GeM) Consortium: Collect >100 NF1-related and/or sporadic MPNST tumors and paired normal tissue/blood from participants consented for whole genome sequencing and data sharing. Display clinical and genomic data across all samples in a cloud-based data exchange to facilitate pre-clinical research directed at identifying therapeutic targets for this tumor type.

The NF Research Initiative at Boston Children's Hospital will contribute:

- 1. Funding to each selected participating site to support the submission of clinical data and samples to the consortium, as follows:
 - a. Clinical data: \$1,000 for each participant recruited.
 - b. Matching tissue samples: \$600 for each participant recruited for submission of tumor sample suitable for WGS (FF resection specimen or cores), matching peripheral blood, and slides for central pathology review.
- 2. Reimbursement for travel expenses for PI of each participating site to attend kickoff meeting of the consortium Steering Committee in Boston (Fall, 2017).
- 3. Funding for central pathology review of all samples (including immunohistochemistry, H&E).
- 4. Funding for whole genome sequencing, RNA-Seq, and copy number analysis (for samples sent to the Coordinating Center; to be performed at Broad Institute in the US and a European site for samples from Europe).
- 5. Funding for genomic analysis by TCGA team at the Broad Institute.
- 6. Funding to host consortium data (clinical, pathology, genomics) in a cloud-based data exchange (each site PI will have secure access).
- 7. An IRB protocol suitable to the needs of this effort (or you may use your own).
- 8. A full-time Program Coordinator and a full-time Admin Assistant to coordinate consortium meetings and logistics.

Participating sites will contribute:

- 1. An individual to serve as site PI and serve on the Steering Committee
- 2. At least 5 MPNST samples (NF1-related or sporadic; tumor AND paired normal, and peripheral blood plasma for studies of ctDNA) with clinical data including clinical history, imaging results, and pathology report. Recruitment goal is at least 5 participants per site over 18 months or less.
- 3. Slides from FFPE to be sent to the Coordinating Center for central pathology review.
- 4. Signed participation agreement regarding terms of participation, including that consortium sites will agree to consortium rules about publication as determined by the Data Access and Use Committee (composed of consortium members).



Governance:

- 1. Steering Committee which will meet initially in person and subsequently by teleconferences organized by the coordinating center.
 - a. Steering Committee will elect a chair and establish consortium rules.
 - b. The Steering Committee will develop and approve a charter for the consortium
- Data Access/Use Committee to screen proposals from within the consortium about use of the shared data.
 - a. Authorship of consortium publications will be negotiated by this committee.
 - Anticipated publications are related to "Clinical natural history and outcomes" and "MPNST pathology" and "MPNST genomics." (Participants can select their area of preference to be part of a publication writing group.)
 - c. Data will be made public (to the extent possible) once the consortium has completed publication of initial findings.

Requirements to participate in this RFA:

- Able to contribute MPNST and paired normal samples. Application will require data on how many patients a site had each year with NF1 clinical diagnosis and MPNST or sporadic MPNST (list grade; years 2014, 2015, and 2016)
- Willingness to participate in collecting clinical data; application will ask if your site currently has a study coordinator who can facilitate chart review, etc.
- Interest and ability to contribute intellectually to the effort. Application will require designation of a PI to represent each site on the Steering Committee and include updated NIH biosketch for this individual.
- Samples collected for each patient must include: one or more sites of MPNST as a fresh frozen resection specimen; peripheral blood sample; slides for pathology review.
- All participants consented for whole genome sequencing and sharing of clinical and genomic data through a dedicated portal.

To Apply:

- Application information available by email or on our website
- Funding levels are not negotiable.

Email: NFresearch@childrens.harvard.edu

Website: https://www.nfresearch-childrens.org/

The NF1 Research Initiative is made possible by an anonymous donation