

Information about the Network and how to get involved

The [United States Network of Pediatric Multiple Sclerosis Centers](#) (NPMSC) is comprised of [core clinical centers](#) and a data coordinating and analysis center ([DCAC](#)). A core clinical center is designated in the infrastructure grant application to the National Multiple Sclerosis Society (NMSS) and is supported by the grant to collect and enter all pediatric-onset demyelinating disease patient data into a central registry. The principal investigator (PI) and optional co-principal investigator (co-PI) from each center serve on the network steering committee. The network steering committee oversees the research mission of discovering the causes, investigating determinants of remyelination and neuroprotection, advancing therapeutics and improving outcomes of Pediatric MS (<http://usnpsc.org/aboutTheNetwork.html>). The steering committee approves research projects that utilize network resources and data. One vote from each core clinical center and the DCAC are required for network decisions on matters such as selecting a network chair and approving a concept to be developed into a network research study.

The NPMSC also works with [affiliate clinical centers](#). Affiliate centers work with the core clinical centers without involvement in the infrastructure award. These affiliate centers may work with core centers in a couple of different ways. First, the affiliate center PI may have proposed a project in collaboration with the network, and with the use of network data. Second, the affiliate center may have joined an existing network project as an enrolling center. It is also possible for an affiliate center to be involved in both ways. While affiliate centers do not sit on the steering committee and do not have a vote in network decisions, their contribution to enrollment and scientific input is highly valued. The PI/co-PI of any enrolling center (core or affiliate) is included as a co-author on manuscripts or abstracts utilizing data from their center.

The network infrastructure is financially supported by the NMSS and supplemented with federal grants and funding from industry, foundations, and philanthropy. The DCAC contracts with the NMSS and subcontracts with each of the core clinical centers to distribute funding based on patient enrollment in the network registry and follow-up visits performed. If affiliate centers join an existing project as an enrolling center, they subcontract with the prime awardee of the grant or project and receive funds from that source. An affiliate center may also obtain funding for a specific analysis or manuscript and subcontract with the DCAC to perform their project utilizing network data and resources.

The NMSS and the network have a mutually established goal of further increasing funding from federal grants, industry and philanthropic organizations. The network and NMSS are interested in inviting investigators to propose collaborative research concepts (i.e., early ideas for projects) to the network steering committee with the goal of developing these into grants and projects. The projects would be executed by core centers and the DCAC plus the submitting center and any additional centers required for recruitment and supported by the funding source.

Avenues to get involved

For specific steps on avenues to get involved, please contact pedms@hsc.utah.edu

Propose a project

Proposing a project to the network steering committee begins with a two-page concept proposal (including a hypothesis, specific aims, design, and possible funding sources) followed by a presentation, question and answer session, a closed discussion by the steering committee and a vote. For a concept to be presented to the steering committee, it must have been endorsed by at least one [core clinical center PI or co-PI](#). If the project is approved to move forward, it is developed into a full application by the proposing investigator in conjunction with the steering committee and a feasibility and budget committee, and ultimately submitted for funding.

Participate in a network study

Some projects conducted by the network require additional clinical centers to meet enrollment goals. At the discretion of the lead principal investigator/prime awardee and if funding permits, additional centers may be added to meet enrollment goals. In this case, the additional center(s) become affiliate clinical centers.

Propose a manuscript

Since 2011, data have been collected in the network's main database. This valuable resource has been utilized to conduct numerous analyses that have been published in prominent journals. External collaborators are invited to submit writing plans for manuscripts that utilize network data. This may require funding support for the DCAC, typically obtained through institution grants. The network executive committee periodically reviews ongoing and requested manuscripts to prioritize the work. It is possible that the executive committee will determine that a manuscript should not be pursued, for example, due to overlap with other manuscripts in progress, insufficient detail in the plan, or other concerns with the analysis. When a manuscript reaches a high priority level, the network's process for planning and carrying out analysis begins. Depending on the priority assigned and the current workload, work on the manuscript could start within weeks of submission of the plan, or it could take several months.

Join the Difficult Cases Webinar

In conjunction with the NMSS, the network clinical centers co-host a monthly [Pediatric-Difficult-Case-Webinar](#) where healthcare providers discuss and get advice from others on handling specific cases of pediatric neurological disorders they are seeing in their clinics. Common discussion topics are differential diagnosis and treatment dilemmas. This webinar is open to all interested clinicians. To join the Difficult Cases Webinar, or to submit a case, please contact Darren.Ball@nmss.org (<https://www.nationalmssociety.org/For-Professionals/Clinical-Care/Professional-Education/Pediatric-Difficult-Case-Webinar>).

Becoming a core center within the Network

If, through additional funding, the opportunity arises to expand the network, the NMSS and the network will release a Request for Applications to become a core clinical center. This is a competitive process where applying centers must demonstrate their clinical center's ability to recruit adequate numbers of patients, to participate in multi-center clinical research, to write grants or other funding proposals, and to make additional contributions to further network research efforts. Centers can also demonstrate potential contributions to the network based on a history of participation in network activities, with priority in the following order: (1) a project proposed and taken through to grant submission, (2) participation in enrollment/follow-up of patients through a network study, (3) proposing and writing a manuscript, and (4) participation in the difficult case webinars. Applications will be reviewed by a panel consisting of individuals selected from the steering committee, the NMSS, patients/families, or other individuals. If selected to become a core clinical center, the applicant joins the network steering committee, subcontracts with the DCAC to receive infrastructure support and is expected to uphold established performance measures for core centers including attending network meetings, ensuring timely and accurate data entry and developing manuscripts and grants.

For any questions related to this document or the network in general, please contact pedms@hsc.utah.edu