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**Ataxia Centers of Excellence (ACE)**

**Mission**

The goal of the National Ataxia Foundation (NAF) Ataxia Centers of Excellence (ACE) program is to designate exceptional regional centers providing comprehensive care and services for individuals affected by ataxia and their families. In addition to providing expert clinical care for ataxia and ataxia-related disorders, the Centers should be engaged in clinical research and/or clinical trials, provide professional and lay education to patients and their families in the areas they serve, and work with NAF locally and nationally in its efforts to continually improve the lives of those affected by ataxia.

**Designation Criteria**

**Comprehensive Clinical Care**

* Must have a coordinated ataxia clinical care team to provide comprehensive multidisciplinary ataxia care that includes two or more neurologists with specialized training/experience in ataxia or movement disorders.
* Offer Referral Services, such as, but not limited to:
	+ Genetic Counseling and Testing
	+ Urology
	+ Cardiology
	+ Ophthalmology
	+ Psychiatry/Psychology
	+ Family Planning & Reproductive Health
	+ Trained Rehabilitation Specialists (e.g., Physical and Occupational Therapy, Speech Language Pathology)
	+ Social Services
* Provide clinical care for at least 30 ataxia patients annually.

**Professional Training and Research**

* Provide clinical education and training to health care professionals (e.g., fellows, nurses, PTs, social workers) through formal rotations and/or fellowships.
* Must have a designated clinical coordinator who dedicates some time to ataxia and demonstrate active engagement in ataxia clinical trials and/or research studies.

**Community Education and Outreach**

* Engage in community-based educational or outreach events for individuals with ataxia, care partners and families (e.g., participate in fundraisers, patient meetings, support groups).
* Promote patient engagement in clinical research studies and clinical trials.

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**Benefits & Requirements After Designation as NAF Ataxia Center of Excellence**

**Benefits:**

* Given a NAF ACE Branded Plaque for public display in clinic.
* Approval to use designation in institutional or clinic promotional materials and external communications or applications.
* Recommended to patients on NAF website as an Ataxia Center of Excellence.
* Listed in NAF-recommended clinical trial site registry to be provided to NAF industry partners.
* Will receive regular updates on new and ongoing clinical trials, referral programs, grant opportunities, and pertinent updates on ataxia standard of care.
* Become part of a network of ataxia clinical experts that can provide support, guidance, and new opportunities for collaboration for improved ataxia clinical care and research.

**Requirements:**

1. **Annual** **Patient Population Report:** The purpose of this report is to better understand the regional distribution of ataxia patients and to provide guidance for industry partners on site selection for clinical trials. This report will require each center to enter the number of patients with specific ataxia disorders that were seen in the previous year. No other clinical or demographic information will be required about patients (e.g. 7 unique SCA1 patients seen in 2022). A templated report will be provided to each designated center and the first report will be due 13 months after the designation start date.

2. **Annual Clinical Study and Trial Report:** The purpose of this report is to assist NAF in providing guidance and recruitment material for our patient membership seeking participation in clinical research and trials. Centers will provide an annual summary report of ongoing clinical research and trials at your site. The first report will be due 13 months after the designation start date.

3. Participate in at least one local or virtual patient support group per year.

4. Provide current contact information of clinic lead neurologists for periodic NAF communications.

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**Application Process for NAF Ataxia Centers of Excellence Designation**

Ataxia clinical sites seeking a NAF Ataxia Centers of Excellence (ACE) designation must submit a written proposal as described below to kelsey@ataxia.org with the subject line “ACE Application.” The NAF accepts applications three times per year. If approved, designated centers will maintain their recommendation for five years from the date of approval, at which time they will be required to re-submit a proposal for review. Selected sites must meet annual reporting requirements to maintain ACE designation.

**REVIEW AND SCORING OF APPLICATIONS**

Applications will be reviewed by a committee composed of NAF staff, representatives from the NAF Medical Research and Advisory Board, an industry representative from NAF’s Drug Development Collaborative, and a patient representative. All applications will be scored, using the following criteria:

1. The quality of the overall application and services provided.
2. Engagement in clinical research and trials.
3. Geographic diversity.
4. History of commitment to NAF Community Outreach and Education OR demonstration of plan to commit to NAF Community Outreach and Education.

The scoring of applications is part of an internal review process. Therefore, scores will not be shared with any site applying for designation, regardless of whether the site is given designation. Following review of the application, applicants not selected for designation may request a virtual meeting to discuss avenues to strengthen future applications.

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| **Application Cycle** | **Application Due Date** | **Decision Communicated By** | **Start / End Date** |
| December 1, 2022 – March 31, 2023 | End of Business Day, March 31, 2023 | April 30, 2023 | May 2023 / April 2028 |
| April 1, 2023 – July 31, 2023 | End of Business Day, July 31, 2023  | August 31, 2023 | June 2023 / May 2028 |
| August 1, 2023 – November 30, 2023 | End of Business Day, November 30, 2023  | December 31, 2023 | January 2024 / December 2028 |

**APPLICATION INSTRUCTIONS**

***Proposals should be no more than 6 pages*** *and should include the following sections. You may type directly into this word document.*

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1. **Ataxia Clinic:** Describe your ataxia clinic, including location and space. Please describe number of days per month dedicated to ataxia-specific clinic time.
2. **Patient Population Served.** Briefly describe the region and population you’re currently serving. How many ataxia patients are you seeing per year? Please estimate numbers of patients by disease type in the chart below and add any relevant rows. What percentage of FTE is dedicated to ataxia patient care? Please provide any relevant details on the diversity of the patients served.

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| **Ataxia Diagnosis** | **Estimated # of Unique Patients seen Annually in Clinic** |
| Total Number of Patients |  |
| Dominant Spinocerebellar Ataxias  |  |
| Recessive Ataxias |  |
| X-linked |  |
| Acquired Ataxias (due to injury, autoimmune, toxicity, or vitamin deficiency) |  |
| Episodic Ataxias |  |
| Hereditary Spastic Paraplegia |  |
| Idiopathic Ataxia / MSA-C |  |

1. **Clinical Staff:** List ataxia clinic key personnel, their roles, and any relevant specialized ataxia or movement disorder training current staff have received.
2. **Clinical Services:** List relevant clinical and professional services provided to ataxia patients through designated ataxia clinical staff or through referral within your institution or partnered health care systems. Example patient services may include, but are not limited to: Genetic Counseling and Testing**,** Urology**,** Cardiology**,** Ophthalmology**,** Mental Health Services**,** Family Planning & Reproductive Health**,** Physical and Occupational Therapy, Speech Language Pathology, Social Services)
3. **Professional Training:** Describe professional training or mentorship provided to health care professionals (e.g., fellowships, rotations, etc.).
4. **Research:** Briefly describe any research activities and involvement in previous and/or active clinical trials.
5. **Community Education and Outreach:** Briefly describe any engagement and/or sponsorship of events, groups or activities relating to ataxia community support, education, or outreach.

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