

**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:
	+ at least twoneurologists with specialized training/experience in ataxia/movement disorder

**OR**

* + at least .5 FTE combined dedicated clinical time to ataxia between neurologist and Advanced Practice Practitioners
* 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
	+ Palliative Care
* Provide clinical care for at least 30 ataxia patients annually and patients must span a variety of ataxia types.

**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 research 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.

**Applicant, please check off appropriate option:**

\_\_\_\_ The application I am submitting meets the designation criteria listed above

\_\_\_\_ The application I am submitting does NOT meet the designation criteria listed above

**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.

**Applicant, please check off appropriate option:**

\_\_\_\_ The applicant recognizes the benefits of ACE Designation and plans to meet the requirements

\_\_\_\_ The applicant does NOT recognize the benefits of ACE Designation and does NOT plan to meet

 the requirements

**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 research@ataxia.org with the subject line “ACE Application.” The NAF accepts applications two 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.

**Applicant, please check off appropriate option:**

\_\_\_\_ I understand the deadlines and review process

\_\_\_\_ I do not agree with the deadlines and review process

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| --- | --- | --- | --- |
| **Application Cycle** | **Application Due Date** | **Decision Communicated By** | **Start / End Date** |
| March 1, 2024 – May 31, 2024 | End of Business Day, May 31, 2023 | July 15, 2024 | August 2024 / July 2029 |
| June 1, 2024– September 30, 2024 | End of Business Day, September 30, 2024  | November 30, 2024 | December 2024 / November 2029 |

**APPLICATION INSTRUCTIONS**

***Proposals should be no more than 8 pages*** *and should include the following sections. You may type directly into this Word document.*

1. Please state the full name, title and valid email address for the addressee who should receive the application results:
2. Please enter a valid shipping address for receiving packages at the clinic/hospital/institution:
3. Is the site in the United Kingdom\*? \_\_\_\_\_

\*The answer to this question will not affect your review score.
If the clinic is in the UK, please **also** consider applying to be an Ataxia UK accredited Ataxia Center via this link: <http://www.ataxia.org.uk/healthcare-professionals/ataxia-centres-specialists/>.

1. **Please provide the name, title, percent of clinical FTE dedicated to ataxia, and email contact information for your center’s neurologists and Advanced Practice Practitioners who have specialized training and experience treating ataxia.** Optionally,please include if any key personnel have specific specialties such as pediatrics or veteran-care**:**

|  |  |  |  |
| --- | --- | --- | --- |
| **Name, Title** | **Percent of Clinical FTE dedicated to ataxia (ex: .25 FTE)** | **Email Address**  | **(Optional)** Specific specialties such as pediatrics or veteran-care |
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|  |  |  |
| --- | --- | --- |
| **Name** | **Title** | **Email** |
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1. **Please provide the name and contact information for your clinic’s research coordinator(s):**
2. **Ataxia Clinic:** Describe your ataxia clinic, including location and space. Please describe number of days per month dedicated to ataxia-specific clinic time.
3. **Patient Population Served.**

Briefly describe the region and population you’re currently serving:

Please provide any relevant details on the diversity of the patients served:

Please estimate numbers of patients by disease type in the chart below and add any relevant rows. How many ataxia patients are you seeing per year? Please indicate in the chart.

|  |  |
| --- | --- |
| **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, Palliative Care)
3. **Professional Training:** Describe professional training or mentorship provided to health care professionals (e.g., fellowships, rotations, etc.).
4. **Research Description:** Briefly describe any research activities and involvement in previous and/or active clinical trials.
5. **List of Research:** Please fill in the tables below with a focus on Ataxia-related research during the last 5 years. One row in each category is filled out in red as an example.

*Natural History Studies*

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Year Started** | **Disease** | **Principal Investigator** | **Funding Source** | **# Participants (Optional Field)** |
| 2022 | SCA1, 2, 3, 6, 7, 8, 10 | J. Doe | NAF | 7 |
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|  |  |  |  |  |

*Clinical Trials*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **From** | **To** | **Disease** | **Principal Investigator** | **Sponsor** | **Phase** | **Status** |
| 2021 | 2024 | SCA3 | J. Doe | Pharma Company | 3 | Recruiting |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |

*Research funding*

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **From** | **To** | **Project** | **PI** | **Co-investigator** | **Funding** | **Budget** |
| 2021 | 2022 | Late-onset ataxias | S. Holmes | J. Watson | NAF | 35 000 USD |
|  |  |  |  |  |  |  |
|  |  |  |  |  |  |  |

1. **Community Education and Outreach:** Briefly describe any engagement and/or sponsorship of events, groups or activities relating to ataxia community support, education, or outreach.
2. Should your site be selected, enter the following information as it should appear on NAF's patient facing ACE website.

|  |  |
| --- | --- |
| Name of Site |  |
| Address |  |
| Valid Website |  |
| How patients should schedule an appointment (Are referrals required? Are new patients accepted?) |  |
| Phone Number |  |
| Name of specific doctors who specialize in ataxia  |  |

1. **OPTIONAL:** Please email research@ataxia.org with any supporting documents. Examples include: Clinician CVs, Letter of Support, and/or clinic brochures.
2. By submitting this ACE application, I acknowledge that the provided information is accurate to the best of my knowledge and recognize that broad statements about my application (i.e. number of patients seen annually) can be shared with NAF partners.

\_\_\_\_ Yes, I agree

\_\_\_\_ I do not agree, and therefore do not wish to submit an application