



CORE NETWORK OF  
**excellence**  
CARE - OUTREACH - RESEARCH - EDUCATION

# Application Guidance Packet

Application Cycle: 2025

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# Application Instructions

## General guidelines

When completing the application, be sure to read instructions carefully and answer each question with the appropriate information.

Applications submitted with incomplete forms and/or missing information will **not** be considered by the Committee.

## The Ehlers-Danlos Society Contacts

If you require assistance or have questions, please direct your inquiry to [cne@ehlers-danlos.com](mailto:cne@ehlers-danlos.com). A member of staff will assist you as soon as possible.

If you require alternative submission formats, please contact [cne@ehlers-danlos.com](mailto:cne@ehlers-danlos.com) with a brief description for assistance or alternative submission formats.

## Application Form

The main part of the application is in the form of a survey. When applications are open, you can access the survey at this link: <https://redcap.link/CNE-application-form>

If you need to leave and return to your survey response, you must use the survey access code sent to your email. If you encounter problems with this feature, please contact [cne@ehlers-danlos.com](mailto:cne@ehlers-danlos.com).

## Supporting materials

Supporting materials to be considered alongside the application form should be included as an attachment in the “file upload” section. In the “index” section of the application, please include a list of the documents submitted.

Where possible, materials should address the following areas.

*NOTE: Please feel free to use the listed questions as a prompt when generating your materials. These are intended as a guide to ease the application process and are **not** an exhaustive list.*

### Feasibility

- What, if any, steps are required for the proposed CORE Member to meet the Designation Criteria?
  - How will those steps be accomplished? What timeline can be expected?

### Capacity

- How many EDS/HSD patients are seen on average each month?
- What Telehealth infrastructure is available? How will it be used?
- How are patient feedback surveys and research participation facilitated?
  - e.g., in-clinic tablets, written questionnaires that are digitized, take-home flyers, etc.
- Descriptions of physical space, disability access, occupancy, and location.
- Descriptions of the proposed referral pathways and capacity planning to accommodate them.

- Do the practitioners operate in different care systems? How will scheduling and referrals be directed?
- Are there barriers to information sharing (charting systems, etc.)? If so, how do you plan to overcome them?

### *Funding*

- Is any of your care provision/staffing tied to specific funding?
  - If so, please describe in general terms any relevant timing or conditions of the funds that would impact the CORE Member's ability to stay in operation
    - e.g., grant paid out over a fixed number of years, funds that are released under specific conditions being met, etc.

***NOTE:** We do **not** require proof of funding in the form of guarantor paperwork or budgets, etc. Please do not include financial statements in your supporting materials.*

### *Staffing*

We do require a copy of CVs/biographies for all practitioners listed in the application. CVs/biographies should demonstrate education or training, and involvement with the EDS/HSD population. Administrative staff (if applicable) are not required but may be included.

- How many full and part-time staff are involved?
- Will the proposed CORE Member be adding any additional positions?
  - Please indicate how any additional positions may assist in operations.

### *Education*

- Are there examples of a commitment to community education/involvement that can be submitted?
  - e.g., community presentations, educational content on social media, hosted events, flyers and other materials, open clinics/consultations, etc.

***NOTE:** If you have presented or participated in workshops/consultations at an event hosted by The Ehlers-Danlos Society, you may include the event name, year, and a short description of your involvement.*

## Designation Criteria

The Designation Criteria are included in the following sections. They are made of two parts: minimum and supplemental criteria.

The minimum criteria outline The Ehlers-Danlos Society's minimum expectations for CORE Network Members. To be considered for approval by the committee, applicants must demonstrate that they meet *all minimum criteria* listed below.

Successful applicants will also meet the appropriate number of criteria from the Supplemental Criteria list. We encourage applicants to list all supplemental criteria that apply in their submission.

# CORE Network Designation Criteria

The criteria below outline the requirements to receive designation for the CORE Network of Excellence.

## CORE Network of Excellence Minimum Criteria

To gain and retain CORE Program status, applicants will demonstrate each of the following:

| Minimum Criteria  |
|---|
| <b><i>General</i></b>   |
| <ul style="list-style-type: none"> <li>• Members should practice a patient-centered approach to care through:               <ul style="list-style-type: none"> <li>• Listening, validating, and showing a commitment to inclusivity</li> <li>• Offering exceptional care and management options</li> </ul> </li> <li>• Commitment to diagnosing using only the 2017 internationally peer-reviewed criteria, management, and care guidelines               <ul style="list-style-type: none"> <li>• Acknowledging the same commitment for any future updated work that replaces the 2017 criteria</li> </ul> </li> <li>• Multidisciplinary case discussions must occur on a fixed frequency</li> <li>• A demonstrated proficiency in The Ehlers-Danlos Syndromes, by <b>any</b> of the following:               <ul style="list-style-type: none"> <li>• e.g., completion of EDS ECHO, has seen at least 20 EDS/HSD complex patients, publication(s) in peer-reviewed literature on EDS/HSD/comorbidity topic(s), has attended any two Ehlers-Danlos Society conferences with CME credits offered</li> </ul> </li> <li>• Remain up to date on all relevant compliance trainings and certifications               <ul style="list-style-type: none"> <li>• e.g., HIPAA, GDPR, DEI training, etc.</li> </ul> </li> <li>• Members will occupy physical spaces with full disability compliance and the ability to offer adaptations when needed</li> </ul> |
| <b><i>Staffing</i></b>  |
| <ul style="list-style-type: none"> <li>• A minimum of three practitioners</li> <li>• Administrative staff</li> <li>• Designate one member as a CORE Lead to:               <ul style="list-style-type: none"> <li>• Coordinate clinical care and practitioners</li> <li>• Lead multidisciplinary case discussions</li> </ul> </li> <li>• CORE Lead or their designee will attend annual CORE meeting to teach and learn</li> <li>• Facilitate feedback survey for each patient</li> </ul>   |
| <b><i>Research</i></b>  |
| <ul style="list-style-type: none"> <li>• Each Member organization will facilitate patient engagement in research activities               <ul style="list-style-type: none"> <li>• This includes providing patients an opportunity to sign up to research activities with The Society, including the DICE Global Registry and Global Biobank.</li> </ul> </li> <li>• Engaging as a site in multi-site research within the CORE Network</li> </ul>   |
| <b><i>Education</i></b>   |
| <ul style="list-style-type: none"> <li>• Direct patients to educational materials               <ul style="list-style-type: none"> <li>• e.g., flyers, handouts, The Ehlers-Danlos Society website</li> </ul> </li> <li>• At least one attendee from each CORE Member to join the ECHO CNE Program</li> </ul>   |

## CORE Network of Excellence Supplemental Criteria

In addition to the minimum designation criteria, partnering organizations applying to become a Center of Excellence will demonstrate **four to six (4-6)** of the following criteria from any category:

| <b>Supplemental Criteria</b>  |
|---|
| <b><i>General</i></b>   |
| <ul style="list-style-type: none"><li>• Sending a delegate to additional conferences hosted by The Ehlers-Danlos Society<ul style="list-style-type: none"><li>• e.g., Global Learning Conference, International Scientific Symposium, etc.</li></ul></li></ul>  |
| <b><i>Staffing</i></b>  |
| <ul style="list-style-type: none"><li>• Administrative support for coordinating scheduling, referrals, etc.</li><li>• On-staff mental health professional and/or Genetic counselor</li></ul>  |
| <b><i>Research</i></b>  |
| <ul style="list-style-type: none"><li>• Conducting qualitative, quantitative, or mixed-methods research</li><li>• Members must comply with their country-specific regulations for human subject protection</li><li>• Members will express an interest in contributing to published collaborative research in peer-reviewed journals or equivalent processes.</li></ul>  |
| <b><i>Education</i></b>   |
| <ul style="list-style-type: none"><li>• Assisting in dissemination of research findings</li><li>• Speaking or presenting about EDS/HSD at conferences, poster sessions, seminars, etc.<ul style="list-style-type: none"><li>• Including those not hosted by The Ehlers-Danlos Society</li></ul></li><li>• Provide training opportunities for students and healthcare professionals.<ul style="list-style-type: none"><li>• Internships, job shadow, fellowships, etc.</li></ul></li><li>• Demonstrating a commitment to community education</li></ul> |

## Review Process & Timeline

Applications will be completed using online form unless an alternative application method was agreed upon with CNE Program staff.

The first step of the review process involves a brief screening by Program staff to ensure all materials are complete and clear. After verifying the application materials are complete, the application will be sent to a committee that will review the submitted materials. Once a decision is reached, the committee will accept or decline the application.

Successful applicants will receive an acceptance letter and an information regarding next steps. Applicants who were declined in this cycle will receive a letter that the committee has declined their application. Wherever possible, the committee will include feedback to declined applicants that could aid applicants in revising their materials for future application cycles.