



## **Application: Team Telomere's Centers of Excellence (CoE) for Telomere Biology Disorders**

Team Telomere is wholeheartedly dedicated to its mission: The mission of Team Telomere is to empower individuals worldwide impacted by Telomere Biology Disorders with information and support services, to advance improved diagnosis through education and advocacy, and to accelerate the medical and scientific community's research in finding causes, effective treatments, and a path towards a cure. We greatly appreciate your interest in Team Telomere's Centers of Excellence (CoE) for Telomere Biology Disorders.

We are confident that this program will expand our ability and effectiveness to best serve individuals impacted by TBDs.

The goal of this program is to identify centers that are committed to excellence in advancing coordinated care, comprehensive care, advocacy and support, education, collaboration, and research for the TBD community. CoEs will be highlighted as cornerstone centers for patients and clinical centers looking to connect to trusted high-quality care.

Each CoE should designate a team lead. This team lead will be responsible for submitting the application, responding to application follow-up questions, and maintaining communication with Team Telomere regarding updates and renewal.

The application cycle for Team Telomere's Centers of Excellence will be open once every two years starting in February and closing in April (subject to change). Please note that the applications must be submitted through Team Telomere's application platform only. The review committee will consist of the Team Telomere scientific committee members, and patient feedback on centers will be collected through a separate form administered by Team Telomere.

Care centers can expect to hear a response on their care center status in mid-May. This response will either communicate acceptance, follow-up questions, or denial.

Any questions can be directed to [info@teamtelomere.org](mailto:info@teamtelomere.org)

On behalf of the TBD community – thank you for your commitment to advancing care for TBD patients.

## Benefits of Being a Designated Team Telomere CoE for TBDs

- **Formal Listing:** Centers of Excellence will be listed on Team Telomere's official website and CoE heat map. This listing will highlight the details of the center, specialists available, and steps on how patients can get connected, helping patients and other care centers easily find and connect with the center.
- **Increased Visibility:** Team Telomere will regularly communicate about Centers of Excellence through mass and individual communications with the community. Social media posts and direct correspondence with newly-diagnosed individuals will be utilized to increase visibility and patient engagement.
- **Collaborative Network:** Centers of Excellence gain increased access to a collaborative network of other centers dedicated to excellence in the TBD community. Sharing best practices with other members will lead to improved patient care, management, and treatment approaches. CoE meetings will be facilitated by Team Telomere to promote collaboration twice yearly.
- **Expanded Patient Referrals:** Centers of Excellence will experience a growth in patient referrals from other institutions and organizations, resulting in an increased patient base and enhanced clinical experience.
- **Enhanced Credibility:** Being part of Team Telomere's Centers of Excellence program will enhance the center's credibility within the scientific and medical community.
- **Recognition for Leading Efforts in TBD Space:** Centers of Excellence will be recognized as leading efforts in the TBD field. By being part of this dynamic network, CoEs will contribute to advancements in comprehensive and coordinated care, while advancing education, advocacy, and research, establishing themselves as forefront and cornerstone centers in the field.

## Overview of Requirements:

	Required	Recommended
<b>Specialists</b>	<ul style="list-style-type: none"> <li>• Hematologist and/or Oncologist</li> <li>• Bone Marrow Transplant Physician</li> <li>• Pulmonologist and/or Lung Transplantation Physician</li> <li>• Hepatologist and/or Liver Transplantation Physician</li> <li>• Gastroenterologist</li> <li>• Dermatologist</li> <li>• Otolaryngologist / Oral Medicine specialist</li> <li>• Genetic Counselor</li> <li>• Social Worker</li> </ul>	<ul style="list-style-type: none"> <li>• Immunologist</li> <li>• Ophthalmologist</li> <li>• Endocrinologist</li> <li>• Neurologist</li> <li>• Nutritionist</li> <li>• Reproductive Endocrinologist</li> <li>• Obstetrician / Gynecologist</li> <li>• Urologist</li> <li>• Surgical Oncologist</li> <li>• Palliative Care Specialist</li> </ul> <p>*For any speciality not available at the center, please describe the process and approach that you take to ensure patients can access needed clinicians.</p>

<b>Management</b>	Ability to conduct or easily access the following monitoring modalities: <ul style="list-style-type: none"> <li>• Blood tests (including CBC, liver function tests, ec.)</li> <li>• Bone marrow biopsy</li> <li>• Pulmonary function testing</li> <li>• CT / MRI / ultrasound</li> <li>• Contrast echocardiography</li> <li>• DXA scan</li> <li>• Endoscopy</li> <li>• Fibroscan ultrasound</li> <li>• Magnetic resonance (MR) elastography</li> <li>• Nasolaryngoscopy</li> <li>• Esophagogram</li> </ul>	<ul style="list-style-type: none"> <li>• Dental assessments</li> <li>• Eye and Retinal Exam (Complete including widefield fluorescein angiography)</li> </ul> <p>*For any management modality not available at the center, please describe the process and approach that you take to ensure patients can access needed testing and surveillance.</p>
<b>Treatment</b>	<ul style="list-style-type: none"> <li>• Hematopoietic cell transplantation</li> <li>• Lung Transplantation</li> <li>• Liver Transplantation</li> <li>• Interventional Radiology</li> </ul>	<ul style="list-style-type: none"> <li>• Laser photocoagulation and/or vitreoretinal surgery</li> </ul> <p>*For any treatment not available at the center, please describe the process and approach that is taken to ensure patients can access needed therapies.</p>

## Application Form

### General Information

What is the name, address, and main telephone number of the applicant institution:

- Name:
- Mailing Address:
- Main Telephone Number:

Approximately how many individuals diagnosed with a TBD does your institution serve?

How many of those individuals are between the ages of 0 and 18 years?

How many are over 18 years?

### Team Lead Information

- Name
- Clinical Specialty
- Mailing address
- Phone number
- Email
- Link(s) to academic / clinical bio
- TBD Experience (in 5 to 7 sentences)

## Center's Specialist Information

For every Required and Recommended Specialist (as in the table above) provide the following:

- Physician name
- Email
- Link(s) to academic / clinical bio
- TBD Experience (in 2 to 3 sentences)

## Management and Treatment

Please check the box for all management and treatment modalities (as in the table above) available at your center. For any modality not available at the center, please describe the process and approach that you take to ensure patients can access needed management and treatment.

## Short Answer Questions

1. Why do you feel your center is a good candidate to be a Center of Excellence? (500 word limit recommended.)

## Coordinated Care

1. Beyond electronic medical records, discuss how your team implements coordinated care. (150 word limit recommended.)
2. Describe how you update other CoE team members about a patient's medical status. (150 word limit recommended.)
3. Discuss how you update the patient's primary care physician (PCP) about a patient's medical status. (150 word limit recommended.)
4. Discuss how you assist patients in arranging appointments and scheduling their management testing including scans and blood work. Additionally, what plan does your center have for following up with patients who do not adhere to recommended management guidelines? (150 word limit recommended.)
5. Discuss the structure, frequency, and content of team meetings at your center. (150 word limit recommended.)
6. Given the multisystem clinical presentations of TBDs, discuss how care is coordinated across specialities at your center. (300 word limit recommended.)

## Comprehensive Care

1. Describe and evaluate the effectiveness of your diagnostic and genetic counseling approach for individuals suspected of having a TBD and diagnosed with a TBD. (300 word limit recommended.)
2. Discuss how you approach conversations with family members of an individual diagnosed with a TBD who are at risk of having a TBD. (150 word limit recommended.)
3. Discuss your approach towards patients presenting with diagnostic challenges of TBDs (e.g. no identified genetic cause of disease, clinical telomere length testing between the first and tenth percentile, inconsistent or lack of clinical features, etc.). (300 word limit recommended.)
4. Describe the psychosocial resources that are available to patients in your center (e.g. palliative care teams, mental health specialists, social workers, etc.). (150 word limit recommended.)
5. Describe the approach, structure, and effectiveness of your children to adult care transition. (150 word limit recommended.)
6. Explain how the second edition *Telomere Biology Disorder: Diagnosis and Management Guidelines* are used to guide diagnosis, management, and treatment at your center. (150 word limit recommended.)
7. Explain how your institution ensures patient-centered care, including personalized treatment approaches and support for patients and their families. (150 word limit recommended.)

## Advocacy and Support

1. Discuss how your center connects individuals diagnosed with a TBD, their family members, and their caregivers with Team Telomere? (Please discuss this topic across the age spectrum and across specialties.) (150 word limit recommended.)
2. Discuss how information on the second edition *Telomere Biology Disorder: Diagnosis and Management Guidelines* are communicated to individuals diagnosed with a TBD, their family members, and their caregivers. (150 word limit recommended.)

## Education

1. Discuss your current efforts in educating a) regional, b) rural, and c) referring care centers. Please cite specific examples and list regional, rural, and referring care centers as appropriate. (300 word limit recommended.)
2. List the professional medical conferences that key specialists on your team have attended. (Please cite specific talks or posters presented if appropriate.) (150 word limit recommended.)
3. Provide examples of programs or events organized by your institution to educate your institution, surrounding communities, and the broader public on TBDs (e.g grand rounds, Team Telomere community days, etc). (150 word limit recommended.)

### Collaboration

1. Provide specific examples of cross-disciplinary collaborative projects and initiatives at your center. What has been the impact of this cross-disciplinary work for TBD patients? (150 word limit recommended.)
2. Discuss how you connect and collaborate with other care centers that treat TBD patients. If selected as a Center of Excellence, how would you collaborate with other Centers of Excellence? Please cite specific examples as appropriate. (150 word limit recommended.)

### Furthering Research

1. Please use this space to discuss TBD related research efforts being carried out at your institution. (500 word limit recommended.)
2. What do you see as being the areas of greatest need in TBD research over the next five years? How will your institution contribute to advancement in these areas? (300 word limit recommended.)
3. How will you encourage patients to get involved in the Team Telomere TBD patient registry, powered by RARE-X? (150 word limit recommended.)

### Concluding Questions

1. How else can we support you in providing the best TBD care possible – individually and as an institution?
2. Outline specialized programs your institution offers for patients with TBD that are not captured elsewhere in this application. (300 word limit recommended.)
3. Please use this space to list additional comments in support of your center's application.

## Required CoE Initiatives

These initiatives are **mandatory** for Team Telomere Center of Excellence designation. Please check off each item to confirm these have been covered in your application responses.

- ☐ Provide coordinated and comprehensive care for TBD patients as defined by having a systematic process for:
  - ☐ a) streamlining internal team communication,
  - ☐ b) updating of PCP and CoE team members,
  - ☐ c) arranging needed tests and appointments, and
  - ☐ d) coordinating care across specialties.
- ☐ Use the *Telomere Biology Disorder: Diagnosis and Management Guidelines\** to guide diagnosis, management, and treatment in a patient-centered manner for TBD patients and their families.
- ☐ Hold at least 1 internal team meeting with TBD specialists at your center each quarter of the year (i.e. four meetings in total annually).
- ☐ Connect patients, their families, and caregivers to Team Telomere for educational, support, RARE-X, and advocacy resources.
- ☐ Educate at least one regional, rural, and referring care center annually. (This should be a formal educational initiative spanning at least one hour in length.)
- ☐ Openly and transparently collaborate with other Centers of Excellence.
- ☐ Renew CoE application every 2 years. (The renewal process is a condensed version of the full application.)
- ☐ Maintain contact with Team Telomere every 6 months regarding CoE updates, changes, and developments.

## Additional CoE Initiatives

This is a checklist of additional programmatic opportunities that can be incorporated into a CoE. Please check off opportunities your center plans on accomplishing over the next two years. While these are not required, checking at least 2 to 3 boxes is **highly** recommended. For all opportunities checked, please provide a brief (2 sentence) explanation.

- ☐ Collaborate with Team Telomere to host at least one patient-facing event within the next two years
- ☐ Host one internal, organizational Grand Round related to TBDs, or other internal-facing educational program, formal or otherwise
- ☐ Attend (at least 3 center team members) the Team Telomere Scientific Summit in 2024
- ☐ Provide CoE feedback related to areas of improvement for the CoE program to Team Telomere at least once per year with Team Telomere staff/leadership.
- ☐ Create/maintain web page on hospital website about CoE team, with link to [teamtelomere.org](http://teamtelomere.org)
- ☐ Participate in at least one TBD research initiative or at least one TBD peer reviewed publication in the next 2 years

- ☐ Submit proposal for TBD specific discussion/talk/presentation at specialty society meeting (e.g. American Society of Hematology annual meeting, American Thoracic Society annual meeting, Transplantation & Cellular Therapy conference, etc.)

***\*Telomere Biology Disorder: Diagnosis and Management Guidelines***

We understand that the field of Telomere Biology Disorders is rapidly advancing and approaches must be tailored to the complexities of individual patients. However, given the need to be comprehensive, Team Telomere strongly recommends using the *Telomere Biology Disorder: Diagnosis and Management Guidelines* to guide diagnosis, management, and treatment.