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September 2020

Dear Board Member,

Welcome to the Team Telomere Board of Directors! We are excited to have you join our team, and we look forward to moving the mission of Team Telomere forward with your help. Included in this packet, you will find information about our organization, Board member roles/responsibilities, a calendar of upcoming meetings, events and more.

We meet quarterly as a Board, and each subcommittee also meets regularly, as outlined in the calendar. Your attendance and participation is necessary for us to continue to grow and develop as an organization. Because we are a working Board, we are thankful in advance for the time you will commit to support the mission of Team Telomere. There may be special projects in addition to our regularly scheduled meetings, and we will draw on your strengths to help us complete projects, plan events, etc. Below you will learn more about the history of Team Telomere, it's mission, and recent accomplishments.

## Mission

Our mission is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders, to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers.

## **Our History**

Team Telomere, formally Dyskeratosis Congenita Outreach, was started in 2008 when researchers from the National Institute of Health, including Dr. Blanche Alter and Dr. Sharon Savage, brought together patient families for support and to help research move forward. The premise was set by our Founder, Nancy Cornelius that "no one is ever alone". For the ten years since the forging of the organization that has always remained consistent. In 2016, we went from a Board run organization to committee run, and hired our first paid employee. We recognized that where our roots were firmly planted in outreach and community we need to keep our goals reaching ever forward with research, and so we changed our name to Team Telomere. We have seen tremendous growth by always staying close to our beginnings and always looking to do more, to make each day better for families, to help research move forward with our scientists, and to support each person in their journey by being bound to our mission and meeting our community in the most impactful ways possible.

## 2019 Highlights

- We hosted our first Family Days this year which were held in Miami, Cincinnati, Boston, Houston, Boise, as well as the UK and Ireland.
- Grants have been awarded to Team Telomere because our projects are unprecedented within the rare disease community.
- Care packages have been sent all over the world, providing comfort and resources to patients in all stages of the disease.
- We were able to award The Million Dollar Bike Ride grant in the amount of \$62,664.
- Our Clinical Guidelines have been distributed to physicians worldwide, properly equipping our ever expanding network of treating physicians.
- Families and physicians joined together in our annual Dine, Dance and Donate event for a truly special evening with many meaningful moments.
- Two scholarships were awarded to members of our community, thanks to the generosity of the Cornelius family.
- The website and newsletters continue to provide patients, caregivers, and physicians with the most up to date information.
- Our Legacy group is continually strengthening, offering a safe place for our bereaved families.
- And Giving Tuesday speaks for itself, raising over \$53,000 for Team Telomere!

While our plans have adjusted and travel has been postponed because of COVID-19, we are continuing to move our mission forward in new & creative ways.

## 2020 Highlights to date

- Uplifting Athletes Grant, \$20,000 awarded to Dr. Abhishek Mangokar
- Million Dollar Bike Ride Grant, \$62,000 raised, RFA to be announced September
- Clinical Guidelines committee formed and working toward an updated edition in Summer 2021, 8 new chapters, including focus on health and wellness
- Collaboration with NIH for caregiver study

falie Stevens & Colleen Vertait

- Keeping our community connected during COVID-19 with Community Check-ins, Family Chats, Legacy calls
- Care Package Program, 37 packages sent in 4 countries
- CoRDS Registry, developing patient registry to launch January 2021
- Improving Donor Management via DonorPerfect
- Second Annual Nancy Cornelius Scholarship Fund awarded
- Penn Biotechnology Group project to expand our reach in the Idiopathic Pulmonary community

We have expanded and restructured to accommodate growth in our organization, and you will be an integral part of our plans and ultimate success moving forward. Please take the time to carefully review this onboarding packet, and do not hesitate to reach out with any additional questions. We look forward to working with you to make the best of 2020 during these unprecedented times.

With hope,

Executive Director

esident & Chair of Legacy

## VISION FOR 2020:

A world where every person affected by Telomere Biology Disorders, including the individual, caregiver, researcher, and clinician have care, community and resources readily accessible to change the course of the disease.

## Mark Your Calendar \*Guaranteed to change

Annual Board Meeting- September 28, 2020 @6pmET via Zoom

Executive Board Meeting- December 2020, TBD

## **2021 Board Meetings**

- January 21, 2021 @7pmET via Zoom
- \*April 15, 2021 @7pmET via Zoom
- September 16, 2021 @7pmET via Zoom
- November 18, 2021 @7pmET via Zoom

MDBR- June 2021 Date TBD

Dine, Dance, and Donate-October 2, 2021, Rochester MN

## Family Days:

Toronto April
St Louis April
CDA July
Brisbane October
UK November
Camp Sunshine TBD

## Committees:

Communication Committee: 2nd Tues/month
Development 1x/week

G&N Committee: Each Quarter

Outreach Committee: North America bi-monthly UK Quarterly Pacific Quarterly

Board members are responsible for their travel.

## **Team Telomere Structure**

#### **Executive Director:**

Katie Stevens

#### **Communications Director:**

Haley Gonzalez

## **Board of Directors:**

- Colleen Verkaik, President
- Kendall Davis, Vice-President
- Ryan McCormack, Treasurer
- Jeni Colter, Secretary
- Eric Villeneuve
- Allison Kiene
- Nicole Bjerke
- Tim Olson
- Suneet Agarwal
- Ashley Yee
- Heather Kagel

#### **Consultants:**

Maggie Rowe, Education Liaison Attorney \*

## **Global Ambassadors:**

- Pacific, Megan Stephens and Rachel Little
- Spain, Dr. Rosario Perona
- Germany, Dr. Christian Kratz
- Canada, Amy Pilon
- UK, Jacquie Roskell and Claire Brookes

## **Outreach Committee**

- Jeni Colter, Chair
- Ambassadors
- Colleen Verkaik
- Katie Stevens

## **Governance & Nomination**

## Committee

- Allison Kiene, Chair
- Ryan McCormack
- Jeni Colter
- Katie Stevens
- Kendall Davis
- Colleen Verkaik
- Lisa Helms-Guba

## **Finance Committee**

- Ryan McCormack, Chair
- Colleen Verkaik
- Kendall Davis
- Katie Stevens

## **Medical Advisory Board**

- Suneet Agarwal, Chair
- Sharon Savage
- Alison Bertuch
- Rodrigo Calado
- Jakub Tolar
- Tim Olson
- Ann Garrity Carr
- F. Brad Johnson
- Mrinal Patnaik

## **Development Committee**

- Kendall Davis, Chair
- Joanna Winsborough
- Katie Stevens
- Colleen Verkaik
- Heather Kagel
- Allison Kiene
- Ashley Yee

## **Communications Committee**

- Haley Gonzalez, Director
- Sonia Bhala
- Melinda Goodwin
- Colleen Verkaik
- Nicole Bjerke
- Katie Stevens

## EXPECTATIONS OF THE BOARD AS A WHOLE

The mission of TEAM TELOMERE, INC. is to provide information and support services to families worldwide affected by Dyskeratosis Congenita and Telomere Biology Disorders, to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers.

As the highest leadership body of the organization and to satisfy its fiduciary duties, the board is responsible for:

- Determining the mission and purposes of the organization
- Selecting and evaluating the performance of the Executive Director
- Strategic and organizational planning
- Ensuring strong fiduciary oversight and financial management
- Fundraising and resource development
- Approving and monitoring TEAM TELOMERE INC.'s programs and services
- Enhancing TEAM TELOMERE INC.'s public image
- Assessing its own performance as the governing body of TEAM TELOMERE, INC.

## EXPECTATIONS OF INDIVIDUAL BOARD MEMBERS

- Each individual board member is expected to know the TEAM TELOMERE, INC.'s, policies, programs, and needs
- Faithfully read and understand the organization's financial statements
- Serve as active advocates and ambassadors for the organization and fully engage in identifying and securing the financial resources and partnerships necessary for TEAM TELOMERE INC.'s to advance its mission
- Leverage connections, networks, and resources to develop collective action to fully achieve TEAM TELOMERE INC.'s
- Maintain a get/give annually of a minimum of \$500
- Help identify personal connections that can benefit the organization's fundraising and reputational standing, and can influence public policy
- Prepare for, attend, and conscientiously participate in board meetings, and must attend a minimum of two board meetings per year
- Participate fully in one or more committees Board Member

## BOARD MEMBERS ARE ALSO EXPECTED TO

- Follow the organization's bylaws, policies, and board resolutions
- Sign an annual conflict-of-interest disclosure and update it during the year if necessary, as well as disclose potential conflicts before meetings and actual conflicts during meetings
- Maintain confidentiality about all internal matters of TEAM TELOMERE, INC.

## **EXECUTIVE BOARD OF DIRECTOR RESPONSIBILITIES**

## President

- Subject to the control of the board, works with the ED ato maintain supervision, direction over the activities, business, etc of the organization.
- Has general powers and duties of management over the officers and committee members, and such other powers and duties as may be prescribed by the board.
- Develop, implement, monitor and assess the orgs programs, including their impact.
- Develop, implement, monitor and assess sound and compliant financial management practices, including budgeting and fundraising, including but not limited to grassroots, grants and individual gifts.
- Develop, inform and support the board and the board committees to carry out their governance functions.
- Works to maintain open communication and relationships with all committees and board members regarding projects, finances, communication, governance, etc...
- Preside over meetings of the Board and Executive Committee

## Vice President

- Works in partnership with President to ensure implementation of President's duties
- Steps in to represent org when President is unavailable
- Works with ED to assess BOD at each Annual Meeting.

#### Treasurer

- Maintain filings and copies of filings with entities such as the Secretary of State,
   Attorney General, State Tax Agency and the IRS among others
- Serve as a signing officer. Sign contracts, checks and credit applications and other such documents on behalf of the org. Before signing, acquire express written permission from the Executive Director.
- Manage or oversee financial affairs; ie: Develop and manage orgs financial policies; monitor security of account. Investigate erroneous purchases and fees; check signing authority, expense reimbursement, credit card usage.
- Prepare/facilitate preparation of the annual budget with the Executive Director and President each fiscal year to ensure success. Regularly monitor actual revenues and expenses incurred against such budget, in monthly finance committee meetings.
- Keep a calendar of filing requirements and deadlines and have clear assignments to help ensure they are all met in a timely manner.

## Secretary

- Timely distribution of agenda, within 2 days of the meeting.
- Be knowledgeable of organizations records and related materials: Dropbox monitor
- Take minutes at each Board meeting, on occasion will be asked to take \*notes for MAB meetings
- Distribute minutes no later than two days after board meetings to the entire BOD, MAB and Ambassadors in pdf form.
- Oversees COIs at each Annual Meeting

#### CONFLICT OF INTEREST STATEMENT FOR TEAM TELOMERE STAFF AND BOARD

#### Conflict of Interest, Disclosure, and Confidentiality Statement

During the time that I serve on the board of directors or as an employee of Team Telomere, I realize that I will gain access to information that is considered to confidential, proprietary, or both. Team Telomere's confidential information includes, among other things: (1) the personal information of Team Telomere's constituents, (2) patient information, and (3) unfinished research studies commissioned by Team Telomere. Proprietary information includes, among other things: (1) Team Telomere's logos and artwork, (2) Team Telomere's designs, and (3) any other Team Telomere intellectual property.

Since confidential information is crucial to the operation of Team Telomere, and because Team Telomere in some instances has the obligation to protect such information, I agree that I will not use, publish, or disclose such information during or subsequent to my employment or participation on the board of directors, and that I will preserve the restricted nature of this information except to the extent that it becomes publicly available, or is otherwise lawfully obtained outside the scope of this agreement from third parties.

Further, since proprietary information is crucial to the operation of Team Telomere, I agree that I will not use such information without the consent of the Team Telomere Board. I will not use Team Telomere's logos, artwork, designs, or other intellectual property for personal endeavors or endeavors involving organizations other than Team Telomere. Also, I agree that any Team Telomere logos, artwork, designs, or other intellectual property that I create or help create will be the property of Team Telomere. Team Telomere will have full ownership over such property—I will have no proprietary rights.

Additionally, as an employee or member of the board of directors, I realize that I have an obligation to disclose and eliminate (if necessary) any potential or actual duality of interest or conflict of interest.

Below, I have listed all community organizations, nonprofit corporations, or charitable programs that I or a member

Team Telomere. The term "relation as a significant donation of more to consultant or independent contract."	elationship with, or that have sought or may in the futu- onship" means any relation with a person or organizate than \$100), employment (such as a volunteer assignment) or fiduciary (such as a board member or officer). ildren, or other individual living in the same household	tion, whether financial (such nent, part-time job, or as a The term "immediate
with respect to confidential inform	understand, and agree to Team Telomere's policies as nation, proprietary information, and conflict of interest e and accurate to the best of my knowledge.	
Printed Name	Signature	Date

## **Team Telomere 2020 APPROVED Budget**

General &				2020 Family	2020 Proposed	Designated 2020	2040/2020	
Administrative	2019 Account Activity	YTD Thru October	2019 Budget	Days/Events	Budget		Comparison	Notes
								Touey (\$75 per month) Kim Bianco, Mainline
	Accounting Fees	3,558	2500	-	3,400			Accounting \$2500 (\$208.33 per month)
	Bank Service Fees	581	0		600			PNC, Paypal, International POS fee (debit fees), Facebook Fee
	Bank Service Fees	581	"	-	600	1		Alliance Member Services, \$200 per month, Harbor
	Insurance Liability, D &O	2,500	2,400	-	2,925			Compliance (\$1,724 per year)
	Audit- Charitable Reg.							, , , ,
	Compilation	0	0	-	3,000			Per Bruce
								Grace at Work \$50/month plus projects, Constant
	Marketing	9,131	١		5,000			Contact (\$49/mo), Any Promo (\$1926), Lawrence Phillips-Tshirts(\$1512), Eureka Science(\$2520)
	Organization Dues	9,131	0	-	500			\$50-NORD
	Organization Bade	, and the same of	Ť		000			400 HOND
	Outside Contract Services	205		-	0			
	Postage, mailing Services	1,899		-	2,000			Traveling Mailbox (\$550/year)
	Supplies Other	1,666		-	1,000 2,000			Dropbox, Grant Station, Donor Perfect, Zoom
Total	Ottiei	29,698		-	20,425			
Payroll		25,090	10,000	_	20,720	1		
	Employer Expense	1,793	0	-	2,500			Employer Taxes
	Payroll	24,622	12,960	-	26,000			Katie-\$20,000/yr, Haley-\$6,000/yr
	Payroll Tax	26		-	0			
Total	ED Bonus	Included in payroll 26,441	11,781 22,960	7% over \$40k	up to 7000 35,500			
Scholarships &	Grants	20,441	22,960	-	35,500			
ocnorarismps &	Nancy Cornelius							
	Scholarship	2000	2,000	-	2,000	2,000		Cornelius Family Donation
	Young Investigators Grant			-	10,000			
Total			2,000	-	12,000			
Care Packages	Postage	2,249	0	_	2,500			
	Supplies	2,249	0		500			
Total	Сирриос	2,706		-	3,000			
Symposiums,								
Events &Travel	2019			2020				
	Annual Board Meeting 2019	3,100	2,000	Annual Board Meeting 2020	700			Combine with Camp Sunshine
	Dine, Dance and Donate	3,100	2,000	Dine, Dance and	700	\$10,000 Repeat		Combine with Camp Sunstaine
	2019/CCCTAA	10 Bazillion	0	Donate 2020	15,000	Naming Sponsor		
	ASH 2019	5000		ASH 2020	6000			I would like development to find a new sponsor for ASF
	Global Genes 2019	1200	1,500	Global Genes 2020	1200	1,200		Global Genes Allowance
	Mayo Clinic NORD- Boston		0					
	Telomere Meeting		· ·					
	combined with Annual		I					
	Meeting trip		<u> </u>	ESH Meeting	3000			Combined with UK Family Day
				Misc.Travel	2,000			
			<u> </u>	Clinical Guidelines	10,000			***Ultragenyx Grant/Outside Funding***
Total			25,000		37,900	1		
Family Days			+			+	Mayo is requesting	
	Miami, FL	1000	I	Rochester, MN	500	8,500	funding	Global Genes Grant, to be split among Family Days
	Cincinnati, OH	1000	i e			0,000	randing	Days
DDD	Boston, MA			Couer D'Alene, ID	2000		_	
	Houston, TX/TCT ASBMT							
	Symposium	2000	-			_	*T10-11-11	
	LIK/Iroland	2000	I	Manahastar III	1000		*Travel Scholarships	Combined with ESH meeting
	UK/Ireland Boise, ID	3000 400	1	Manchester, UK Camp Sunshine	1000 13000	10,000	only	Combined with ESH meeting *Camp Sunshine earmarked for TT
	Travel Scholarship	2.800	0	- Jamp Junstille	13000	10,000		Camp Sunstance cannaixed tot 11
	I	2,000	10,000		16,500	1		
Total			10,000					
Total Budget Total			106,960		125,325			

## BY-LAWS OF TEAM TELOMERE, INC.

## **ARTICLE 1 - Name, Incorporation, Officers**

<u>Section 1. Name</u>: The name of the corporation is: Team Telomere Outreach, Inc. referred to hereinafter by "TT".

<u>Section 2. Incorporation</u>: TT is organized as a not-for-profit corporation under the laws of the state of New York.

Section 3. Principal Office: The principal office of TT shall be located at: 1562 First Avenue 205-4093

New York, NY 10028

or at such other place as the Board of Directors may from time to time determine.

TT shall maintain a registered office in New York as required by the General Laws of New York, Chapter (Code number). TT may also maintain other offices at such other places as the Board of Directors may determine or as the purpose of TT may require.

## **ARTICLE II - Purposes**

The purposes for which TT is formed, as set forth in its Articles of Organization, are to conduct the following activities which are exclusively charitable, educational, and scientific within the meaning of Section 501 (c) (3) of the Internal Revenue Code of 1986, as amended, including:

- 1. To disseminate timely and accurate information about Team Telomere (herein referred to as "TT") to patients, family members, physicians, and other interested parties.
- 2. To provide means for patients and relatives to share experiences, support one another, and improve their medical care.
- 3. To encourage, advise, and establish standards for clinics specializing in the diagnosis and treatment of Dyskeratosis Congenita and other telomere biological disorders.
- 4. To encourage and foster biomedical and other pertinent research on Dyskeratosis Congenita and other telomere biological disorders.
- 5. To aid and encourage formation of regional and international Chapters and to provide assistance and guidance to enhance their effectiveness.
- 6. To undertake all actions as deemed appropriate by the Board of Directors to carry out the foregoing purposes to the extent permitted under state and federal law.

## **ARTICLE III - Membership**

There shall be no members.

#### **ARTICLE IV - Board of Directors**

<u>Section 1. Powers and Duties</u>: The Board of Directors shall have general power to manage and control the affairs and property of the Corporation and shall have full power, by majority vote, to adopt rules and regulations governing the action of the Board and shall have full power and complete authority with respect to the distribution or payment of the moneys received by the Corporation from time to time.

## <u>Section 2. Number, Composition, and Term of Office:</u>

- a. The Board of Directors shall consist of not less than five (5) or more than eleven (11) directors. The number of directors may be changed by vote of a majority of the entire Board but no decrease may shorten the term of any incumbent director(s).
- b. The Board of Directors shall be composed of the Officers, the Chairpersons of the Standing Committees, plus other Directors.
- c. Directors shall be elected by majority vote of the membership at its annual meeting for a term of three years. Beginning upon election, each Director shall serve for said term and until his/her successor shall have been duly elected and qualified.

No Director shall serve more than two consecutive terms as Director, except that s/he may be elected an officer for a term extending beyond the second term as Director. A Director who has served two consecutive terms shall be eligible for re-election one year after expiration of his/her second term.

Each year, one-third of the Directors shall be elected. At the first election following adoption of these By-laws, one-third of the Directors shall be elected for one year, one-third for two years, and one-third for three years. Beginning at the second annual meeting, and thereafter, elections of Directors shall be for terms of three years.

Section 3. Nomination and Election of Directors: The Nominating Committee shall decide upon a slate of directors and shall present such slate to the Board of Directors not less than twenty (20) days prior to TT's regular Annual Meeting. Upon written request of at least one member of the Board made to the Nominating Committee not less than ten (10) days prior to the said annual meeting, additional names may be placed in nomination and presented to the Directors of the Corporation. The Nominating Committee shall thereafter present such slate or slates to the regular members of the Corporation for election at the Annual Meeting.

Nominees for Chapter representatives on the Board shall be present or former members of Chapter Boards, who are currently active in Chapter affairs, but need not be members of the Chapter Council.

Each year, the Board of Directors shall appoint a member of the Board of Directors to be international liaison to TT affiliates in other countries.

The following members shall be ex-officio of the Board and shall not be included in the number of directors to be elected: one representative of the Medical Advisory Board, one or more members of the Advisory Council, if and when such council exists.

<u>Section 4. Qualifications</u>: Directors shall be members of TT in good standing.

<u>Section 5. Vacancies</u>: In case of any vacancy on the board of Directors, a successor to fill the unexpired portion of the term may be elected by a majority of the remaining Directors. The Board may hold such a vote at any meeting or via unanimous written consent; it need not hold the vote at the Annual Meeting.

<u>Section 6. Removal</u>: Following written notice, a member of the Board of Directors may be removed by approval of two-thirds of the Directors whenever such member has failed to attend three consecutive meetings of the Board without justifiable cause or when his/her actions have not been in the best interests of TT.

In the case of removal of the Executive Director, the action must be initiated by no less than one-third (1/3) of the Directors and taken by two-thirds (2/3) vote of the full Board of Directors. If the vote is for removal, a minimum of 60 days shall be allowed for termination when the action results from a review of performance, although may be immediate in the event of self-dealing, willful misconduct or recklessness, TT shall have no further financial obligations.

Section 7. Compensation: No Director shall receive compensation or salary in any form for his/her services but shall be reimbursed for authorized and documented expenses.

## **ARTICLE V - Board Meetings**

<u>Section 1. Regular Meetings</u>: The Board of Directors shall meet at least four (4) times per year, which includes the Annual Meeting. Other meetings may be held by means of telephone conferences or equipment of similar communications by means of which all Directors participating in the meeting can hear each other. Participating in this type of meeting shall constitute presence in person.

Directors shall be notified in writing of the time, place, and agenda for regular meetings at least fourteen (14) days in advance of said meetings.

<u>Section 2. Special Meetings</u>: Special meetings of the Board of Directors may be held at any time and place upon call of the Chairperson of the Board, Chairperson of TT or by the Secretary upon written request of a majority of the directors. Special meetings may be held by means of telephone conference or similar communication equipment.

Notice of the time, place, and purpose of the Special meeting(s) shall be given to each Director at least ten days before said meeting.

<u>Section 3. Quorum</u>: A quorum shall consist of a majority of the Directors.

<u>Section 4. Required Vote</u>: An affirmative vote of a simple majority of those present shall be necessary for the passage of any resolution. A Director may not vote by proxy.

<u>Section 5. Action Without Meeting</u>: If Directors shall vote by unanimous written consent to any action to be taken by the Board of Directors, such vote shall have the same force and effect as if taken at a duly called meeting.

#### **ARTICLE VI - Officers**

<u>Section 1. Number and Qualification</u>: The officers of the Corporation shall consist of the Chairperson of the Board, one or more Vice Chairpersons, Secretary, and Treasurer, together with such other officers, if any, the Board of Directors may from time to time appoint. Officers must be elected from among the Board of Directors. No person may hold more than one office in the Corporation concurrently.

<u>Section 2. Election and Term of Office</u>: The officers shall be elected for two year terms by the Directors.

<u>Section 3. Vacancies</u>: In the case of any vacancy in any office, a successor to fill the unexpired term may be elected by the Board of Directors.

<u>Section 4. Other agents, etc.</u>: The Board of Directors may appoint, from time to time, such agents as it shall deem necessary, each of whom shall hold office during the pleasure of the Board, and shall have such authority and perform such duties and receive such reasonable compensation as the Board of Directors may determine.

<u>Section 5. Removal</u>: All Officers and Agents of the Corporation shall be subject to removal at any time by the affirmative vote of a two-thirds majority of the whole Board of Directors.

<u>Section 6. Powers and Duties of the Chairperson of the Board</u>: The Chairperson of the Board is the Chief Executive Officer of the Corporation and shall have general charge and control of all its business affairs and properties. S/he shall have the power to call special meetings and to constitute special committees and make appointments to standing committees. S/he shall preside at all meetings of the Board of Directors: sign and execute all authorized bonds,

contracts, and other obligations in the name of the Corporation: and be an ex-officio member of all committees.

<u>Section 7. Powers and Duties of the Vice Chairperson of TT:</u> The Vice Chairperson of TT shall have such powers and shall perform such duties as may be assigned to him/her/them by the Board of Directors. S/he shall act in the role of Chairperson of the TT in the Chairperson's absence or disability.

Section 8. Powers and Duties of the Secretary: The Secretary shall act as a secretary of all meetings of the members and the Board of Directors and shall keep the minutes of all such meetings. S/he shall attend to the giving and service of all notices of the Corporation and shall perform all the duties customarily incident to the office of Secretary, subject to the control of the Board of Directors, and shall perform such other duties as shall be assigned to him/her from time to time by the Board of Directors.

Section 10. Powers and Duties of the Treasurer: The Treasurer shall have custody of all funds and securities of TT which may come into his/her hands. S/he shall keep or cause to be kept full and accurate accounts of receipts and disbursements of TT, and shall deposit all moneys and other valuable effects of the TT in the name and to the credit of TT in such banks or depositors as the Board of Directors may designate. Annually and whenever else required by the Board of Directors, the Treasurer shall render a statement of accounts. S/he shall at all reasonable times exhibit TT books and accounts to any Officer or Director of TT and shall perform all duties incident to the position of Treasurer subject to the control of the Board of Directors and shall, when required, give such security for the faithful performance of duties as the Board of Directors may determine.

<u>Section 11. Compensation</u>: No officer shall receive compensation for service but shall be reimbursed for authorized and documented expenses.

#### **ARTICLE VII - Committees**

Section 1. Standing and Other Committees: The Board of Directors may, by resolution, designate committees, including committees not referred to in these By-laws. Each committee shall be chaired by a Director of the Corporation. In addition to such Special Committees as the Chairperson of the Board and/or Board of Directors may from time to time authorize, there shall be the following Standing committees: Executive; Nominating; Fund Raising; Membership; Chapter; Professional Education; Public Awareness; Medical Advisory; Legislative; and By-laws.

<u>Section 2. Executive Committee</u>: The Executive Committee has the authority to act on behalf of the Board and shall meet at the discretion of the Chairperson of the Board. The Executive Committee shall be comprised of the Chairperson of the Board, and two other Directors selected by the Board of Directors.

<u>Section 3. Nominating Committee</u>: The Nominating Committee shall consist of the Chairperson of TT and two (2) other members elected by the Board of Directors at the regular meeting of the Board following the annual meeting. The Nominating committee shall present for approval by the Board and a slate of nominees for Directors and Officers.

<u>Section 4. Development Committee</u>: The Development committee's responsibility is to assure that existing and new programs are adequately funded to assure the viability of the organization over the long term. Toward that end, the committee is responsible for

- A. Fund-raising programs
- B. Grants management
- C. Management of fund-raising special events
- D. Input to the Board of Directors in drafting long-range organizational plans.

<u>Section 11. Medical Advisory Committee</u>: The Medical Advisory Committee shall recommend to the Board of Directors appointments to the Medical Advisory Board, shall act as liaison with the Medical Advisory Board, and shall perform such other functions relating to medical concerns that may be assigned to the Committee by the Chairperson of the Board, the Chairperson of (company), or the Board of Directors.

## **ARTICLE IX - Advisory and Honorary Boards**

<u>Section 1. Medical Advisory Board</u>: The Board of Directors may designate one or more persons (including physicians, researchers, psychologists, social workers, or counselors) who are significantly involved in the treatment of those affected by TT and/or their families, to act as a Medical Advisory Council to TT and to make recommendations regarding TT's Grants Program. The Chairperson of the Medical Advisory Board shall be a non-voting member of TT's Board of Directors. No dues are required to be paid by these members.

<u>Section 2. Advisory Council</u>: The Board of Directors, may by resolution designate one or more persons who are significantly interested in the welfare of those affected by (disorder name) or their families to act as an Advisory Board to (company). Members of this council may be persons of talent, special skills or experience, position, rank, influence, connection or demonstrated interest in (company): Recommendations to the Board may come from Directors, members of the Medical Advisory Board, Chapters, staff, and members. No dues are required to be paid by these members.

The Council is advisory in function. Members may be asked to assist in any program of (company), to give professional guidance, counsel, or advice.

<u>Section 3. Honorary Board</u>: An Honorary Board of former members of (company) Board of Directors and others whose name would lend influence to (company) may be appointed to an Honorary Board by (company) Board of Directors.

<u>Section 4. Chapter Council</u>: (Company) shall have a Chapter Council for the purpose of encouraging the establishment and viability of Chapters in each state, district, territory, and possession of the United States, in accordance with these By-laws and the policies of (company).

Each chapter shall designate a representative to serve as a member of the Chapter Council. In order to facilitate attendance, said representative shall be designated prior to the Annual Meeting. Each representative shall be entitled to one vote. For the first Chapter Council meeting after the adoption of these By-laws, the Chapter representatives authorized at the time shall be recognized as members of the Chapter Council as current Chapter Representatives until the Chapters shall confirm.

The term of office shall be two years, beginning upon designation by the Chapter and ending when his or her successor shall have been designated, no later than one week prior to the second annual Chapter Council meeting thereafter.

Responsibilities: to work with TT staff and the board of Directors to:

- 1. Establish, develop, and maintain a Chapter in each state, district, territory and possession of the United States.
- 2. Define the number and composition of regional groupings of Chapters;
- 3. Plan and conduct regional meetings and programs;
- 4. Plan and conduct an annual meeting of the Chapter Council;
- 5. Develop and implement programs of (company) in accordance with these By-laws, (company) policies and standards, and under the direction of the Board of Directors;
- 6. From time to time review and evaluate the programs, policies, and activities of the Chapters and to facilitate the development of programs, policies and activities among the Chapters;
- 7. Transmit to the Board of Directors recommendations concerning programs, policies, and activities designed to further the purposes and goals of (company).

Officers: The officers of the Chapter Council include the following:

1. Chairperson: The Chairperson of the Chapter Council shall be elected by the Chapter Council and shall serve as a Director of (company). The Chairperson shall preside at the Annual Meeting of the Chapter Council and shall oversee the programs and activities of the Council.

- 2. Vice Chairperson of the Chapter council: a Vice Chairperson shall be elected by the Chapter council to serve in the absence of the Chairperson and to perform such duties as delegated by the Chairperson from time to time. If the Chairperson is unable to attend a Director's meeting, he or she may delegate a Vice Chairperson of the (company) to attend the meeting as a guest representing the Chapter Council.
- 3. Secretary. The Secretary, elected by the members of the council, shall record the minutes of the Council, send notices of meetings, shall be Chairperson of the Agenda Planning committee, and have such other powers and duties as may from time to time be assigned by the Council Chairperson.

The terms of office for the officers of the Chapter Council shall be renewable two year terms. No person may serve more than two consecutive terms.

## **ARTICLE X - Chapters (Regions)**

<u>Section 1. Formation</u>: The Board of Directors shall be empowered to designate one or more groups of interested people to act as Chapters of TT. A Chapter is a local unit with a specific area designated by the board of Directors.

<u>Section 2. Purpose</u>: A Chapter is organized and operated exclusively to act locally for the benefit of, to perform the functions of, and to carry out the purposes of the (company).

<u>Section 3. Responsibilities</u>: A Chapter will conduct all activities in an ethical manner as mandated in the (company) Chapter Guidelines, Affiliation Agreement, and other binding documents between (company) and its Chapters.

<u>Section 4. Non-U.S. Chapters and Affiliates</u>: Chapters and Affiliates outside the United States may be authorized from time to time. A Chapter or Affiliate outside the United States will conduct all activities in an ethical manner as mandated in the (company) Chapter Agreement. Chapter by-laws, and other binding documents between (company) and its Chapters, and in accordance with applicable local law. Membership moneys do not cross national boundaries, and will be used within the country in which they were collected.

## **ARTICLE VI - Contracts and Commitments**

<u>Section 1. Authority</u>: Unless specifically authorized by resolution by the Board of Directors, no officer, agent, or member of the Board of Directors, shall have the power or authority to bind TT by any contract or engagement or pledge its credit or financially obligate it for any purpose in any amount. Contracts include agreements with terms material to the operations or commitments of TT or extend a commitment on behalf of TT in excess of one year.

<u>Section 2. Signatories</u>: All checks or drafts drawn on (company) accounts shall be signed in accordance with the resolutions of the Board of Directors.

## **ARTICLE XII - Corporate Seal**

<u>Section 1. Seal</u>: The seal of TT shall be circular in form and shall have inscribed therein the name of the TT, the year of its organization, and the word "(state name)". Duplicate copies of the corporate seal may be provided for use in the different offices of the Corporation, but each copy shall be in the custody of the Secretary of the Corporation.

#### **ARTICLE XIII - Fiscal Year**

<u>Section 1. Dates</u>: The fiscal year of the Corporation shall begin on January 1 and end the last day of December.

## **ARTICLE XIV - Restrictions**

<u>Section 1. Activities</u>: TT shall neither have nor exercise any power, nor shall it engage directly or indirectly in any activity that could invalidate its status as a corporation exempt from Federal Income Taxation as described by section 501(c)(3) of the Internal Revenue Code of 1986; or as a corporation, contributions to which are deductible under section 170(c)(2) of the Internal Revenue Code of 1986.

<u>Section 2. Funds</u>: No part of the net earnings of TT shall inure to the benefit of, or be distributable to its members, Directors, officers, or other private persons, except that the Board of Directors shall be authorized and empowered to pay reasonable compensation for services rendered and to make payments and distributions in furtherance of the purposes set forth in TT's Certificate of Incorporation.

## **ARTICLE XV - Amendments**

The Board of Directors shall have the power and authority to amend, alter, or repeal these Bylaws or any provisions thereof, and may from time to time make additional By-laws.

