

Unleash Your Superpower:

Join the TBRS Community as a Volunteer and Transform Lives!

Make a lasting impact on the lives of individuals affected by TBRS. By dedicating your time and sharing your expertise, you have the power to inspire hope, bring joy, and create a supportive network that transforms lives. Our mission is to support families affected by TBRS and advance research towards interventions. Together, we can create meaningful change. Sign up to volunteer today and be a part of this extraordinary journey.

We have two types of volunteer positions to choose from:

<i>Project Lead Positions:</i>	<i>Helpers:</i>
Project Lead Positions require some level of experience or willingness to learn and a commitment of 1-5 hours per week. These volunteers will help lead projects and have support from other volunteers and TBRS Staff. Training is provided. Ability to commit for one year is preferred. Click on the positions below to read the job descriptions: Fundraising and Development Director (Volunteer) Social Media Manager (Volunteer) Regional Coordinators (Volunteer)	Helpers support Project Leads by taking on smaller tasks while still making a big impact. Click below for positions in the following areas: • Fundraising and Development • Social Media • Regional Coordination • Advocacy

See the pages below for details. Sign up to volunteer [here!](#)

Fundraising and Development Team (reports to the Fundraising and Development Director) Helper Positions (Training is provided by the TBRS Community as needed):			
Thank You Caller: Calls donors to thank them. Requires general knowledge of TBRS Community programming, ability to answer general questions. (3 month - 1 year commitment, 1 hour per week)	Thank You Letter Writer: Writes personalized thank you notes to donors, (cards and postage provided by TBRS Community). (3 month - 1 year commitment, 2-3 hours per month)	Family Fundraiser Coordinator: Organizes their own fundraiser to benefit the TBRS Community. (Short term commitment, depending on your chosen fundraiser)	Grant Prospector: Researches grant opportunities for the TBRS Community. Requires general knowledge of TBRS Community programs and mission. (6 month - 1 year commitment 1-3 hours per week)
Grant Writer: Assists with writing and editing grant applications. Requires exceptional knowledge of our mission, vision, programming, and goals. (6 month - 1 year commitment, Hours vary based on grants)	Sponsor Seeker: Works to obtain sponsorships for several programs, for example: TBRS Summit, Regional Meet-Ups, Adam Parsons Memorial Scholarship, etc. Uses sponsorship materials provided by TBRS Community and creates new materials as needed. (short term commitment, hours vary based on your availability)	Campaign Writer: Writes for fundraising campaigns to be shared on social media, newsletter, website, etc. Requires participation in training provided by the TBRS Community. (6 month - 1 year commitment, 1-3 hours per week)	

Sign up to volunteer [here!](#)

Regional Coordination Team (reports to Kit Church, Research Coordinator and works closely with the Regional Coordinators) Helper Positions (Training is provided by the TBRS Community as needed):		
Meet-Up Host: Coordinates local meet-ups for TBRS families. These may be very informal, and recreational in nature or more structured and include educational aspects. Requires knowledge of the TBRS Community's values, mission, goals, and programs. (Short term commitment)	Caring Ambassador: Identifies families in crisis, sends cards & care packages, & communicates with chair for approval of care packages, tracks who they have reached out to, etc. (6 month - 1 year commitment, 1 or less hours per week)	Social / Support Group Facilitator: Plans and facilitates the TBRS Social or Support Group (6 month - 1 year commitment, 2 hours per month)

Sign up to volunteer [here!](#)

<i>Social Media</i> (reports to the Social Media Manager) <i>Helper Positions (Training is provided by the TBRS Community as needed):</i>			
Photo/Video Content Scout: Peruse social media for good-quality photos, videos, reels, and stories. Reach out to families to see if they are interested in signing the photo release so we can share. Add high-quality photos to our shared drive once photo consent is obtained. (3 month - 1 year commitment, 1 hour per week)	Reel Makers: Creates reels for our social media platforms that increase awareness and educate others on TBRS. (3 month - 1 year commitment, 1 - 3 hours per week)	Content Writer: Write general content for social media, programs, awareness, etc. Requires exceptional awareness of TBRS Community mission, values, goals, and programming. Training provided. (6 month - 1 year commitment, 1 - 3 hours per week)	Storytellers: Shares their story, photos, videos, etc., for our social media platforms to increase awareness and educate others on TBRS. (Can be 1 time or ongoing commitment)

Sign up to volunteer [here!](#)

<i>Advocacy and Policy</i> (reports to Zoey Wisnoski) <i>Helper Positions (Training is provided by the TBRS Community as needed):</i>			
Advocate: Attends advocacy events like Rare Disease Week on Capitol Hill. Requires exceptional knowledge of TBRS, ability to speak publicly. Training is provided to share your story with law makers. (6 month - 1 year commitment, Hours vary)	Media Contact Specialist: Diagnosed individuals and family members who are willing to share their stories with media. Training available. (Commitment and hours vary)	DEI Advisor: Participates in the Rare Disease Diversity Coalition, participates in trainings on DEI, & meets with our team to look at all our programming through a DEI lens. (1 year commitment, 1-3 hours per week)	Awareness Event Host: Attends tabling events on behalf of the TBRS Community, for example autism walks, disability days, etc., & sets up table with informational materials to educate the general community about TBRS. (Commitment and hours vary)

Sign up to volunteer [here!](#)



Project Lead Position

Fundraising and Development Director (Volunteer)

The TBRS Community is seeking a passionate and dedicated volunteer to join our team as a Fundraising and Development Director. Join us and play a crucial role in raising vital funds and expanding our resources to make a lasting impact on the lives of individuals with TBRS.

Responsibilities include:

- Help to develop and execute fundraising strategies to support the TBRS Community's programs and initiatives.
- Identify and cultivate potential donors, sponsors, and partners to secure financial contributions and in-kind support.
- Research grant opportunities, assist in grant prospecting, and contribute to grant writing efforts.
- Build and maintain relationships with existing donors, ensuring proper stewardship and recognition of their contributions.
- Collaborate with the TBRS Community team to create engaging fundraising campaigns, events, and initiatives.
- Utilize our fundraising platforms and channels, including online platforms and social media, to maximize outreach and donations.

Suggested Experience:

- Passion for rare disease advocacy and a commitment to making a difference in the lives of individuals with TBRS.
- Some experience in fundraising, grant prospecting, grant writing, or donor stewardship is preferred, but not required.
- Excellent communication and interpersonal skills to effectively engage with potential donors, sponsors, and community members.
- Strong organizational abilities to manage fundraising campaigns, events, and initiatives.
- Familiarity with fundraising platforms, social media, and online tools is a plus.
- Ability to commit a few hours per week to volunteer work and attend occasional virtual team meetings.

Join us in our mission to create a comforting, inclusive community for TBRS-affected families, advance research efforts, and raise awareness about TBRS. Together, we can make a meaningful difference. To apply, please [click here](#). Training can be provided to enhance your skills and knowledge in fundraising and development.



Project Lead Position

Social Media Manager (Volunteer)

The TBRS Community is seeking a creative and enthusiastic individual to join our team as a Volunteer Social Media Manager. By volunteering as our Social Media Manager, you will have the opportunity to make a real impact by engaging our community, raising awareness, and fostering connections among individuals with TBRS and their families.

Responsibilities include:

- Develop and execute a comprehensive social media strategy to increase our visibility and generate engagement.
- Amplify the voices of the members of our community who share aspects of their TBRS story by sharing their posts.
- Create compelling and shareable content across various social media platforms, including Facebook, Twitter, Instagram, and LinkedIn.
- Collaborate with the TBRS Community team to promote events, fundraising campaigns, and educational resources through social media.
- Utilize analytics tools to measure and track the effectiveness of social media campaigns, adjusting strategies as needed.
- Stay informed about social media best practices, implementing new techniques and technologies to optimize our online presence.

Helpful Skills to Have:

- A passion for making a positive impact in the TBRS Community.
- Strong understanding of social media platforms and their respective best practices, including Facebook, Twitter, Instagram, and LinkedIn.
- Excellent communication and writing skills, with the ability to create engaging and informative social media content.
- Knowledge of social media analytics tools to measure and track the impact of campaigns.
- Creative thinking and the ability to generate innovative ideas for social media content and campaigns.
- Availability to dedicate 1-5 hours per week to manage our social media presence and respond to community interactions.

Join us in our mission. Together, we can make a difference. To apply, [click here](#). Training can be provided to familiarize you with our organization and the specific needs of the TBRS community. Additional training in social media management is also available.



Project Lead Position

Regional Coordinators (Volunteer)

The TBRS Community is dedicated to supporting individuals affected by TBRS and advancing research toward interventions. As part of our commitment, we seek to increase community engagement not only in the United States, but globally. We are seeking enthusiastic individuals to join our volunteer team as Regional Coordinators.

Responsibilities include:

- Welcoming and orienting new members within your region, providing them with information and resources to support their journey with TBRS.
- Educating families about TBRS Community programming, including support, educational, and research programs.
- Gathering regional and local resources and sharing them with community members.
- Assisting with translation of English and local language(s).
- Assisting with organizing local community events, such as meet-ups, educational sessions, and awareness campaigns.
- Recruiting and organizing regional scientists, clinicians, and professionals who have an interest in TBRS, fostering collaboration and advancing research and intervention efforts.
- Facilitating communication between your region and the TBRS Community.
- Engaging in fundraising activities.

Qualifications and Skills:

- Passion for supporting individuals and families affected by TBRS and improving their quality of life.
- Excellent communication and interpersonal skills to engage and connect with community members and professionals.
- Strong organizational abilities and the ability to coordinate and plan events effectively.
- Proficiency in the local language(s) of your region, with translation skills being a plus.
- Ability to work independently and as part of a global team, demonstrating initiative and problem-solving skills.
- Time Commitment: 1-5 hours per week.

This is a voluntary position with flexible hours. The time commitment will vary based on regional needs and events but is expected to be approximately 1-5 hours per week. To express interest in this role, [click here](#).