

Kinslow TUBB4A Foundation Annual Report (2024)

1. Mission Statement and Overview

- **Mission and Vision:** Our mission is to ensure every child affected by TUBB4A-related leukodystrophy has access to equitable treatment options, regardless of location or socioeconomic status, through dedicated research, collaboration, and advocacy.
- **About the Organization:** The Kinslow TUBB4A Foundation is dedicated to supporting children affected by TUBB4A-related leukodystrophy by providing critical information on accessible treatment options and fostering research, collaboration, and advocacy. We serve families worldwide, working to ensure equitable access to care, regardless of geographical location or socioeconomic status, and striving to create a future of possibilities for all children impacted by this rare disorder.
- **Year in Review:** In February 2024, we proudly launched the Kinslow TUBB4A Foundation. Over the course of the year, we expanded our leadership by welcoming a new member to our medical advisory board and a parent representative to our nonprofit board. In partnership with the Children's Hospital of Philadelphia (CHOP), we created and distributed a comprehensive medical pamphlet on TUBB4A-related leukodystrophy to raise awareness and provide vital information to affected families. Looking ahead, we are excited to be collaborating with CHOP on a webinar, scheduled for Q4 of 2024, which will provide further educational resources and support for families navigating this rare condition.

2. Financial Information

- **Revenue Breakdown:**
 - Total revenue for the year: \$7,500
 - Revenue breakdown: Donations through our website, Facebook fundraisers, and Bonfire t-shirt Sales. We are also waiting a \$5,000 grant that we are receiving from the #RareIs Grant.
- **Expenses:**
 - Total operating expenses: \$250.
 - Expenditure breakdown: Website hosting service
- **Surplus/Deficit:** \$7,250

3. Program Highlights

- **Program Achievements:** Detailed information on programs and services provided during the year, including:
 - Kinslow TUBB4A Website was launched in February 2024.
 - Two board members added to Kinslow TUBB4A Foundation

- TUBB4A Medical Pamphlet was created and dispersed and we are currently in the planning process of a TUBB4A Family Webinar in collaboration with CHOP that will take place in Q4 of 2024.

4. Donor and Volunteer Recognition

- **Major Donors:** Jeannie and Frank Duffey, Joni Goen
- **Volunteer Contributions:** Our non-profit board members are all volunteers that spend a significant amount of time investing in the futures of TUBB4A patients. We would also like to thank Aaron Blocker for his mentorship this year.

5. Goals for the Coming Year

- **Strategic Objectives:** Looking ahead, the Kinslow TUBB4A Foundation aims to expand its outreach and impact by growing our research collaborations and developing new educational resources for families affected by TUBB4A-related leukodystrophy. We plan to strengthen our advocacy efforts, increase awareness, and secure additional funding for groundbreaking research. In the coming year, we also aim to host more webinars, build a stronger patient and family support network, and continue fostering partnerships with medical institutions to advance treatment possibilities for all children impacted by TUBB4A.

6. Board and Staff Information

- **Board of Directors:** Sarah Marta - President, Daphne Graskewicz - Vice President, Ryan Marta - Secretary

7. Acknowledgments

- **Grants and Funding:** We are grateful to have been chosen to receive the \$5,000 Amgen #RareIs grant, which will be instrumental in supporting our efforts to provide accessible treatment information, raise awareness, and further research for TUBB4A-related leukodystrophy. This funding will help us continue our mission and expand our impact within the rare disease community.
- **Community Partnerships:** We are proud to collaborate with the Children's Hospital of Philadelphia (CHOP) on several key initiatives, including the creation of a medical pamphlet on TUBB4A-related leukodystrophy and an upcoming educational webinar for affected families. This partnership has been vital in expanding our resources and reaching more families in need of support.

8. Contact Information

- **How to Support:** You can support the Kinslow TUBB4A Foundation by making a donation, starting your own fundraiser, or spreading awareness by sharing our social

media posts and medical pamphlet. Additionally, we are planning to host an in-person fundraising event in 2025, where volunteers will be welcome to join us and contribute their time to support our cause

- **Contact Details:** www.tubb4a.org