

WHAT IS THE TMAU RESEARCH FUND

The TMAU Research Fund is a **restricted** research fund that has been setup with N.O.R.D (*National Organization for Rare Disorders Inc.*). The purpose of the fund is to collect donations that will be used solely towards research into TMAU.

HOW DOES THE FUND WORK?

Donations are forwarded directly to the TMAU Research Fund at NORD. NORD, a well-known and respected organization, offers this banking service, free of charge, to all rare-disease non-profit organizations. Currently, they hold research funds for over 50 other organizations. When the balance of the fund reaches \$35,000.00, N.O.R.D can begin the process of issuing a Request for Research Proposals from research scientists or investigators in the field of TMAU.

Proposal evaluations and award decisions are made by a qualified advisory board. Once a proposal has been selected and approved, N.O.R.D will issue \$30,000.00 for the winning proposal and the balance of \$5,000.00 is kept by N.O.R.D and goes toward their managing expense on the fund and the administrative costs associated with the selection process.

Every month NORD provides a running list of the funds along with the total amount donated in their UPDATE newsletter.

HOW IS THE WINNING PROPOSAL DECIDED?

In the initial Requests for Proposal, scientists are invited to submit a description of their research project along with their professional qualifications. Once NORD has received all the applications their Medical Advisory Committee reviews them and selects the finalists. These finalists are then asked to submit a full grant application from which the Advisory Committee will select who gets the award. The TMAU community will also have the chance to recommend a particular scientist/researcher/project to submit a research proposal.

ARE DONATIONS TO THE FUND TAX DEDUCTIBLE?

Yes. All donations to the fund are tax deductible and a receipt/acknowledgement is sent out to each donor after each donation. You must indicate on your check or money order that your donation is for **TMAU Research**, otherwise your donation may end up in N.O.R.D's general fund.

WHERE DO I SEND MY DONATION?

All donations should be mailed to:

N.O.R.D, P.O. Box 1968, Danbury CT, 06813-1968
Attention: TMAU Research Fund
Make Payable to: NORD-TMAU RESEARCH

For more information on N.O.R.D please visit the online at www.rarediseases.org

N.O.R.D POLICIES REGARDING THE FUND

N.O.R.D has instituted the following policy to ensure that funds do not stay in dormant accounts:

- If the total of donated funds for research on a specific disease is *less than \$1,000 after two years* without significant donations, the fund will be transferred to general research and related activities.
- If the total of donated funds for research on a specific disease is *more than \$1,000 but less than \$5,000* after *four years*, the money will be transferred to research on related diseases. (e.g., neurological, metabolic, connective tissue diseases, etc.)

TRIMETHYLAMINURIA RESEARCH FUND

Established January 2007

- If the total of donated funds for research on a specific disease is *more than \$5,000 but less than \$10,000* after *six years*, the money will be transferred to research on related diseases.
- If the total of donated funds for research on a specific disease is *more than \$10,000 but less than \$15,000* after *eight years*, the money will be transferred to research on related diseases.
- If the total of donated funds for research on a specific disease is *less than \$25,000 in ten years*, the money will be transferred to research on related diseases.

Therefore, we must all work together and make the necessary commitments and sacrifices to make this fund a viable solution. **What will it take?** We must make regular donations - whether they are weekly, monthly, quarterly or, in the case of Planned Giving Programs through employer plans like the *United Way* - annual donations. **We must keep this fund active for ongoing TMAU research and never let it be reallocated** if we want to constructively support research and researchers, and satisfy our intentions.

WHY THIS FUND?

If our intention is to work to find better treatment options and a cure, we must take the necessary steps to increase awareness in meaningful ways and support scientific research initiatives. The way to do the latter is to establish a restricted research fund to which we can all contribute. This fund is not for just one support group or organization but for the entire TMAU community, around the world.

Why not use a standard Trust Account in a regular bank?

Because the monthly fees and balance restrictions will end up costing just as much as the \$5,000 NORD charges and no one is personally willing or able to pick up those fees. In addition, we would not get from a regular bank the heightened visibility in Washington that this commitment brings to the TMAU community or the special technical and professional advisory services that NORD provides.

If 100 people donate \$100.00 per month that would be \$60,000.00 in 6 months, 100 people donating \$50.00 per month would be \$60,000.00 in 1 year.

******* IT IS IMPORTANT THAT EVERYONE INDICATES THAT THEIR FUNDS ARE FOR TMAU RESEARCH. *******

I am a member of the TMAU community, participating in various online forums and actively supporting the TMAU Foundation. I volunteered to coordinate various fundraising activities because there was a need and because I believe in taking personal responsibility. I have worked with the TF and NORD on this project and, effective immediately, have launched the fund with a personal donation. Please join me in being part of the solution.

I plan to provide monthly updates to share our collective progress.

If you have any questions or suggestions, please feel free to contact me directly.

Cheryl Marshall
Email: Cher850@yahoo.com

TRIMETHYLAMINURIA RESEARCH FUND

Established January 2007