



Canadian PKU and Allied Disorders

Hello

Canadian PKU and Allied Disorders (CanPKU) would like to work with targeted sponsors regarding a new program we are launching. The “Drive to Thrive” program will help ensure all of those living with PKU and Allied Disorders are thriving. This program will start with the starter kits that are compiled by CanPKU delivered to clinics to support new diagnosis as well as made available to older individuals who are returning to clinical care or improving their therapeutic treatment. This is a starter kit program we have had in place for many years. We will continue to support our members of all ages to ensure they are doing their best managing their PKU by encouraging clinical interactions, peer support and taking control. Our new initiative will go farther into ensuring members of our community are thriving.

CanPKU recognizes that in the past, often before the year 2000, without the knowledge we have now, the treatment plan for PKU was withdrawn by the medical community who released patients who were of a specific age or stage in life. There was no follow up with these patients and they are essentially “Lost to Care”, sometimes called “lost to follow-up” by clinics. We know better now, benchmarked by the international consensus conference in 2000 which called for “Diet for Life”. We can do better. The hard part is as there was no follow up, we need to locate these “lost” patients. Many will have difficulties maintaining relationships, housing and/or jobs. Some may be struggling with mental health even experiencing physical difficulties and symptoms such as seizures. Their blood PHE levels are out of the treatment range (many severely). They need to return to therapy and clinical care in order to thrive.

They would be amazing candidates for the trials that you are seeking participation in.

We know we share a common goal in finding these individuals. We are requesting an unrestricted additional sponsorship/grant that could be used as we see best in relation to this program. We are hopeful that you can review your budget, dig deep, and assist us with this goal.

We thank you for this consideration.

Regards,

John Adams and Tanya Chute
President and Vice President