



Spare for Rare - Tips for Collecting Pledges

Collecting pledges serves a dual purpose: it's not only raising money for CanPKU so that we can continue our education and advocacy initiatives, but it also gives you an opportunity to explain a little bit about PKU and raise awareness!

Most people will not have heard about PKU or one of our allied disorders, so it is best to start with a short description of what PKU or an allied disorder is and how you are impacted by PKU or an allied disorder. It's best to use your own words and be willing to answer questions, but you can start with something simple like this example:

"PKU is a rare genetic disorder that affects about 1 in 15,000 people and is screened for at birth with the heel prick test (Newborn Screening Program). Patients with PKU cannot process one amino acid in protein, and that amino acid builds up in the blood and is toxic to the brain. Without diagnosis or treatment, most PKU patients will have severe mental deficits when they are very young. However, diagnosis and access to treatments and care means that PKU patients can live full, healthy, normal lives. Unfortunately, many Canadians with PKU do not have access to the treatments they require. To support this worthy cause I will be participating in/hosting a Spare for Rare event and would appreciate anything you are willing to donate. Your pledge will help CanPKU continue to provide support, education and advocacy for PKU patients across Canada."

If someone is unsure whether or not to make a donation, be sure to let them know that every donation helps, \$2, \$5 or \$10 donations add up quickly and are greatly appreciated!

Write down the person's name and the amount pledged **right away!** It is easy to forget the details, especially as more and more donations come in. We have designed a pledge form so that you have a column to record whether (or when) the pledge was received – use it! This will help you remember who you need to collect pledges from at a later date.

Please also note that pledges should be in cash only. If people can only provide a cheque, please ensure that it is made payable to "Canadian PKU and Allied Disorders Inc." or it may not be accepted by the bank when we make the deposit.

It is important to note that **CanPKU is a non-profit organization but NOT a registered charity** – therefore we cannot issue tax receipts for donations made. We are not a registered charity because if we were, we would not be allowed to advocate for better care and access to treatment options. **SUBMITTING THE PLEDGES**

Keep the pledges collected together with the pledge form in an envelope, and keep it in a safe place! **On the day of your local event hand in the pledge form and donations at the registration desk – then enjoy the day! Thank you for helping CanPKU!**