



Spare for Rare - Information for Hosts

Thank you for your willingness to host an event in honour of CanPKU and Allied Disorders. We hope that you will find this to be a worthwhile endeavor, both for yourself and for the other PKU families around you. **Across Canada, May is PKU Awareness Month. We encourage people to try to host events during the month of May, but you are welcome to host an event any time!**

The purpose of Spare for Rare is to raise awareness, to provide an opportunity for PKU families to get together, to raise funds for CanPKU, or all three! Funds raised allow our organization to continue to host quality educational events in all five regions of the country each year, support families living with PKU and allied disorders and advocate for the care and coverage needs in each province. Previous events have included walkathons, gaming nights and trans-Canada bike tours! These fundraisers have raised tens of thousands of dollars for CanPKU over the years and are essential to our operating budget and the sustainability of our organization. Spare for Rare is a fairly easy event to host and is A LOT of FUN!

Organizing a Spare for Rare event does not require a large time commitment and gets even easier the second time around (especially if the venue is the same). Even a small event of 20 people can raise significant dollars and awareness in your community. Participants can collect pledges ahead of time with the form provided, or simply make a donation themselves and enjoy a few games of bowling!

Here are the steps you need to follow in order to become a successful Spare for Rare Event Host.

1. Develop the Concept

- Decide if you want to have just bowling or if you'll add a raffle or prizes.
- Consider getting local businesses to sponsor lanes so that all funds raised by participants go directly to CanPKU.

2. Find a venue

- Finding a venue can be really easy or a bit of a challenge.
- If you're struggling to find a location in your area, reach out to Melissa at fundraising@canpku.org for help!

3. Book Your Venue

- Please fill out the Event Venue Form in its entirety once you have the event venue booked.
- This step is crucial so that we are aware of your event and can support you as much as possible. We cannot have the CanPKU name attached to events we don't know about!
- Email the Event Venue Form to fundraising@canpku.org

4. Spread the word

- Once we receive your form, we will post your event information on our website and will do our best to publicize the event via direct email, our newsletter and our website.
- It is important that you let your local clinic know that you are hosting a CanPKU Event and ask them to also spread the word amongst their patients.
- Please also spread the word by whatever means is feasible to you: write to your local paper, publish information in a school newsletter, post on social media, and email the information to your friends and family.

5. Arrive Early on the Day of the Event

- Registering event participants and collecting their pledges can actually take quite a bit of time.
- Please do your best to verify amounts received by each participant (count the cash they submit compared to their pledge sheet).
- Participants may have many questions for you: how long the event takes, what is happening afterwards, what the money they have raised is going towards, etc. Please allow time to answer questions and mingle with the patients and families.
- Please ensure that all cheques collected are made payable to “Canadian PKU and Allied Disorders Inc.”. It is important that the full name appears on the cheques or they may not be accepted at the bank.

6. Send funds collected to CanPKU.

- Please fill out the **Event Funds Collected Form** and email it to fundraising@canpku.org and Frances.Goodfellow@canpku.org

A few other points:

- Please do not hesitate to host an event, even if you know that you are the only PKU family in your area!
- Collecting pledges is easy and is a great opportunity to spread awareness and knowledge about PKU... even if your family is the only family in the area you may be amazed at the amount of support in your community. Even if only small amounts of a couple hundred dollars can be collected, this will contribute significantly to our overall funds raised, and go far towards spreading awareness about PKU in your community!
- More details and useful information including our “Tips for Collecting Pledges” can be found on our website under “How to Host an Event”.
- Please consider writing a testimonial of your experience illustrating how much time it took, how many people attended, how much money was raised and any other information you feel is key. This is a great way to encourage others to host an event and help CanPKU!