



Well, like 2019-20 before, this year (2020-21) was one for the books. We were faced with the ongoing challenge of COVID-19 - but this time - we saw it coming. Or at least knew that it was possible. This helped us in pivoting to best accommodate the needs of our community while staying apart physically.

We knew we had changes to make - and knew that some things would continue to prosper. First up was our website. Lots of time and effort was put into a new technology platform. This new platform allows us to have an "all in one". We are able to not only offer our community a place to come to obtain information and downloadable items, but a way to advertise events by CanPKU and other supporters around the world. Each registered individual can tailor their experience by adding information about themselves and/or their loved ones with PKU. Our events, the CanPKU Shop, knowledge base, message board and support can all be found on our new website. Read on to see how else we were and are able to use this new platform to help our community.

We continued our work with our members and the Disability Tax Credit. Luckily, with the face to face time being limited, none of our families or adults needed to go to court to win their decisions. Everyone we have assisted has been successful, even if once in a while it took an appeal in writing. We thank Frances Grove Hurst for working with many of our members in order to make this process easier and smoother for those applying. Our new website allows us to make the DTC assistance documentation easier to access for members simply by logging into the site. They can record and track progress in the application in order to help keep everyone on track.

The previous year showed us that COVID-19 would require our membership to have a device to keep in touch with the world. We were able to help families connect with their clinics and other PKUers online by providing 19 Chromecast computers to families or individuals in need. This provided individuals, families and medical professionals the ability to get together and share information. Knowing we would not be able to host our typical information sessions, we implemented a week of webinars during the month of May. We celebrated this week - not only for the wonderful speakers, get togethers, but also for being able to offer this information to everyone in the country - regardless of location or ability to travel. We also supported the first-ever Global PKU Patient conference virtually in September. It was organized by our sister association in Australia with the Global Association for PKU (GAP).

We continued to advocate for improved access to clinical care and treatments and working towards general improvements for PKU across Canada. One of which, we continue to take part in a range of government consultations - which often take place over years - affecting package labels such as requiring and harmonizing rules for disclosure of Aspartame (which is 50% Phe) on more than just diet drinks, but also prescription drugs, over-the-counter drugs,



Because Knowledge Leads to Better Health

www.canpku.org | info@canpku.org  
Suite 180 - 260 Adelaide Street East, Toronto, ON M5A1N1  
1-877-226-7581 | fax 1-877-789-2462

natural health products, etc. Each type of product category requires its own consultation, given the silos of regulations by Health Canada.

We monitor applications for clinical trials and new therapies affecting PKU and are getting ready to make submissions as the only patient organization representing PKU patients and families for Palynziq as it goes through a year-long process at Health Canada about safety, efficacy and quality manufacturing, then onto to health technology assessment (nationally and separately in Quebec), then on to negotiation of price, terms and patient access criteria.

We support and continue to work with companies and new therapies in efforts not only ultimately to bring new therapies to our community, but also bring information regarding clinical trials to Canada - or help our Canadians go to other countries as part of the clinical trials elsewhere. Clinical trials help provide early access to promising new therapies. And clinical trials are necessary to get new therapies approved. We want to thank all those who volunteer to be part of trials in the effort to make things easier for those living with PKU and improve outcomes.

Also we spend much time learning and sharing with other patient organizations including the Best Medicines Coalition, the Canadian Organization for Rare Disorders, the Global Association for PKU, U. S. National PKU Alliance and the Disability Tax Fairness Alliance.

It has been an exceptional year and we wish to thank our members, our Board members, our management members and all volunteers who help make this organization as awesome as we believe it can be. We look forward to continued growth in 2021-2022.