

## PKU knows no borders

August 1, 2017

In July 2017, a regional and several country-based PKU patient organizations from around the world made history by agreeing **to form the first international association for PKU**. This global entity will serve as a supportive umbrella organization to regional and national patient organizations and groups in bridging the gap for PKU worldwide.

The formation of this group is in the early stages. We are pleased to share the following information about the organization at this time.

### Vision

Our vision is that all people living with PKU, despite their origin, will be able to reach their full potential.

### Mission

Our mission is to advance PKU as a global health priority and strengthen PKU associations and groups throughout the world.

### Priorities

As people living with PKU, our priorities are:

- To create a global platform for PKU advocacy that includes ensuring universal access to newborn screening and diagnosis, treatments and comprehensive care;
- To mentor like-minded patient associations and groups and offer best practices and support that are sensitive to their experiences, culture, language(s) and laws;
- To increase collaboration among PKU researchers, scientists, clinicians and patient groups to move basic science and research forward to accelerate new knowledge, treatments, and a cure.

### The Founding Member Organizations are committed to the formation of this new global entity

- Asociación Mexicana de Fenilcetonuria, AC (Mexico)
- Canadian PKU and Allied Disorders
- European Society for PKU
- Corporación PKU Chile
- Grupos de Padres PKU Asociación Civil de Fenilcetonuria de Argentina
- Metabolic Dietary Disorders Association (Australia)
- National PKU Alliance (USA)
- SAFE Associação Amiga dos Fenilcetonúricos do Brasil
- Turkey PKU Family Association



Organizational tasks have been assigned and plans are progressing for meetings over the next year. The founding members would like to thank Abbott Nutrition, BioMarin Pharmaceuticals Inc., Cambrooke Therapeutics, Dr. Schär Medical Nutrition GmbH, Nutricia Advanced Medical Nutrition, and Vitaflo (International) Limited for supporting this initial organizing meeting in Toronto, Canada, to improve the lives of people living with PKU worldwide. During the start-up phase the Canadian PKU and Allied Disorders is acting as financial agent for the global organization.