



Trustees Report for Financial year Ending June 2022

Registered Charity Number: 1184321

Address: 1354 Peartree Cir
OAKVILLE, ONTARIO
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CANADA

Contact Details: Cristian Baigorria

Prepared April 18, 2023

Approved by Trustees: July 20, 2023

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Structure, Governance and Management

The Global Association for PKU is a registered charity with Charity Commission of England and Wales, it is a Charitable Incorporated Organisation (CIO) governed by charitable objects.

Charity trustees:

Name	Date appointed
ALEJANDRO SPATARO	08 July 2019
DENIZ ATAKAY	08 July 2019
TOBIAS HAGEDORN	08 July 2019
CRISTIAN BAIGORRIA	08 July 2019
RONALDO LOPES	08 July 2019
MONIQUE COOPER	08 July 2019
JOHN ADAMS	08 July 2019
JOSE DE JESUS MUNOZ NAVARRO	08 July 2019

Management:

The charity has an executive committee responsible for management of the organisation. The office bearers are voted on at each AGM. GAP has a detailed constitution that describes the governance and management of the organisation including the election of office bearers, member criteria, management and trustee terms and other key governance and management issues. This document can be found in Appendix 1.

Chair : John Adams
Vice-chair: Jose de Jesus Munoz Navarro
Treasurer: Tobias Hagedorn
Secretary: Cristian Baigorria

Trustees generally meet every 2 months. The Executive Committee meets as necessary.

About the Global Alliance for PKU (GAP)

The charity was registered on 8 July 2019. The purpose of the GAP is to: 1) To promote and protect the physical and mental health of sufferers of phenylketonuria (PKU) through the provision of support, education and practical advice and in such other ways as the trustees consider appropriate; and (2) advance the education and understanding of the general public in all areas relating to PKU. The trustees developed a strategic statement to describe how the organisation will fulfil this intent.

GAP Strategy Statement

A regional and several country-based PKU patient organizations from around the world have collaborated to form the first Global Association for PKU – known as GAP. 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 Organization's Vision is that all people living with PKU, despite their origin, will be able to reach their full potential.

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

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.

GAP Activities for 2021/2022 Year

As a newly formed and registered organisation our main activities have been around establishment of appropriate governance and building the profile of the organisation in order to reach our intended targets and increase awareness of PKU worldwide.

Summary of activities:

1. Developed appropriate fiscal and governance procedures to ensure compliance with charity registration requirements and to promote transparency and accountability to members and potential members, including conflict of interest policy, working with sponsors policy, financial management procedures and meeting procedures, member application procedures and fees.
2. Developed membership of the Global Association by accepting applications from the following like-minded PKU patient organisations:
 - (a) DIG PKU (German PKU Association)
 - (b) MDDA (Metabolic Dietary Disorders Association, from Australia)
 - (c) PKU Mexico (Mexican Association for PKU)
 - (d) CanPKU+(Canadian PKU and Allied Disorders)
 - (e) National PKU Alliance (USA)
 - (f) PKUAI (PKU Association of Ireland)
3. Established subcommittees to function as working groups furthering the purpose and strategic intent of GAP. These include:
 - I. Finance and governance

- II. Strategic projects: a) communications, b) audit of current status of Newborn Bloodspot Screening worldwide; and c) membership development.
4. Planned and successfully conducted an international PKU patient meeting in 2022 – called PKUGlobe 2022 from December 8-14th, 2022. This virtual meeting focused on the theme of One World, One Vision and provided awareness, education and collaboration for current and emerging PKU patient groups around the world. Hosted around the globe starting in Australia, Europe and the Americas.
5. The COVID-19 pandemic again limited progress and capacity-building.

The trustees of GAP continue to work to ensure that our activities result in public benefit in particular improved health outcomes for people living with PKU.

Achievements

- Establish communications and fundraising mechanisms
- Strategy for awareness and fund-raising
- Secured funding and progressed planning for the second-ever global PKU patient education and awareness virtual conference
- Established collaborative partnership with member PKU patient organisations around the world.
- Commenced strategy and tools for data collection on status of newborn screening.

Financial Review

As this is our second year of operation and due to the pandemic environment, the GAP have no reserve funds and have not spent any funds this year. The focus on the year has been establishing the appropriate legal structures, policies and procedures for the effective functioning of the charity into the future. In the 2023/2024 financial year we project the following income sources:

- Transfer of residual funds sourced, from sponsorship, by a financial agent (Canadian PKU and Allied Disorders Inc.).
- Fundraising for the global virtual meeting “2021 Global PKU Virtual Scientific Patient Conference” and the PKUGlobe2022 virtual event.
- Fundraising for the global awareness campaign “The Great Protein Challenge 2024”.
- Corporate sponsorships.

All trustees are volunteers with extensive experience in PKU patient organisations and have volunteered in excess of 150 hours in establishing this organisation and continue to volunteer in excess of 20 hours a week in governing and managing this charity.

The charity is not holding any funds on behalf of others.

Declarations

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)	Cristian Baigorria	
Position (eg Secretary, Chair, etc)	Secretary	
Date	July 20 th , 2023	

Charity Commission Annual Return 2022

GLOBAL ASSOCIATION FOR PKU

Charity registration number: 1184321

Most of the information you give in this form will become publicly available on the Register of Charities. Any field that the Charity Commission will not display will be clearly marked.

This document is a record of the information provided in the Annual Return 2022.

Financial period

Financial period start date

01/07/2021

Financial period end date

30/06/2022

Income and spending

Income £

£0

Spending £

£0

Fundraising - professional fundraiser

Did your charity raise funds from the public?

No

Government contracts

During the financial period for this annual return, did the charity receive income from contracts (other than grant agreements) with central government or local authorities?

No

Government grants

During the financial period for this annual return, did the charity receive income from grants from central government or local authorities?

No

Income from outside the UK

Did your charity receive income from outside the UK ?

No

Spending outside England & Wales

Did your charity operate outside England and Wales?

Yes

Select countries/territories your charity operated in during the financial period covered by this annual return

☒ Argentina

☒ Australia

☒ Brazil

☒ Canada

☒ Germany

☒ Ireland

- ☒ Mexico
- ☒ Turkey
- ☒ United States

Argentina	£ 0
Australia	£ 0
Brazil	£ 0
Canada	£ 0
Germany	£ 0
Ireland	£ 0
Mexico	£ 0
Turkey	£ 0
United States	£ 0

Record the total expenditure by country/territory., Please round all figures to the nearest pound (do not enter decimal points or commas)

Spending outside England & Wales

When spending money or working outside England and Wales, did your charity transfer money other than using the regulated banking system?

Spending outside England & Wales

Did your charity have procedures and controls in place to monitor expenditure outside England and Wales?

Are the trustees satisfied that your charity's risk management policies and procedures adequately covered activities and spending outside England and Wales?

Yes

Trading subsidiaries

Did the charity have any subsidiaries?

No

Trustee payments

Did any of the trustees receive any remuneration, payments or benefits from the charity other than refunds of legitimate trustee expenses?

No

Did any of the trustees resign and then take up employment with the charity?

No

Employees' salaries

Did any of your charity's staff receive total employee benefits of £60,000 or more?
Select No if your charity does not have any staff , or does not pay any staff.

No

For your highest paid member of staff only, what was the total value of their employee benefits?

(For example if your highest paid member of staff received £35,000 enter 35000). If you do not have any staff or did not pay any staff, enter 0 (zero)

£0

Volunteers

How many UK volunteers, excluding trustees, did the charity have during the financial period?

0

Financial controls

Did your charity review its internal financial controls?

Yes

Privacy statement

Any information you give us will be held securely and processed only in accordance with the rule on data protection. We will not disclose your personal details to anyone unconnected to the Charity Commission unless:

- you have consented to their release; or
- we are legally obliged to disclose them; or
- we regard disclosure as either (a) necessary so that we can properly carry out our statutory functions or (b) necessary in the public interest.

We may share and disclose information about you with relevant public authorities, regulatory bodies and agencies, outside the Charity Commission but only if:

- we can lawfully do so; and
- we decide that disclosure is necessary for national security, crime detection, prevention, and law enforcement, or other issues in the public interest

Information we collect about you

We will use this information:

To enable us to carry out our statutory functions and duties;

This will include the following actions:

- (a) update, consolidate, and improve the accuracy of our records;
- (b) undertake crime detection and prevention and law enforcement and assist the third parties specified above to investigate or prevent crime and carry out law enforcement;
- (c) data analysis, testing, research, statistical and survey purposes

Information we receive from other sources.

Information we receive from other sources

We may combine this information with information you give to us and information we collect about you.

We may use this information and the combined information for the purposes set out

above (depending on the types of information we receive).

We will ensure that any such disclosure and use is proportionate; considers your right to respect for your private life; and is done fairly and lawfully in accordance with the data protection principles of the Data Protection Act.

The Data Protection Act 1998 regulates the use of 'personal data', which is essentially any information, however stored, about identifiable living individuals.

As a 'data controller' under the Act, the Charity Commission must comply with it. Any changes we may make to our privacy statement in the future will be set out in the replacement version of this form.

Please check back frequently to see any updates or changes to our privacy policy.

Declaration

Your role at the charity (select one):

☒ Trustee

Given names	Cristian
Family name	Baigorria
Telephone number	6472442592
Email	cristian.baigorria@globalpku.org
Date submitted	11/05/2023

It is a criminal offence under section 60 of the Charities Act 2011 for anyone to knowingly or recklessly provide false or misleading information to the commission; this includes suppressing, concealing or destroying documents.