



Trustees Report for Financial year Ending June 2025

Registered Charity Number: 1184321

Address: 1354 Peartree Cir
OAKVILLE, ONTARIO
L6M 2J2
CANADA

Contact Details: Cristian Baigorria

Prepared September 2, 2025

Approved by Trustees: Oct, 2025

Table of Contents

<u>STRUCTURE, GOVERNANCE AND MANAGEMENT</u>	<u>3</u>
<u>CHARITY TRUSTEES:</u>	<u>2</u>
<u>MANAGEMENT:</u>	<u>2</u>
<u>ABOUT THE GLOBAL ALLIANCE FOR PKU (GAP)</u>	<u>2</u>
<u>GAP STRATEGY STATEMENT</u>	<u>3</u>
<u>GAP ACTIVITIES FOR 2019/2020 YEAR</u>	<u>3</u>
<u>ACHIEVEMENTS</u>	<u>4</u>
<u>FINANCIAL REVIEW</u>	<u>4</u>
<u>DECLARATIONS</u>	<u>5</u>

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
LOUISE HEALY	08 July 2019 (resigned 20 APR 2023)
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
LISA MILBERG	11 August 2022 (resigned 16 MAY 2024)
RHONDA CONNOLLY	11 August 2022 (resigned 16 MAY 2024)
BERNADETTE GILROY	13 October 2022 (resigned 27 APR 2023)
CATHERINE WARREN	16 May 2024
SARAH GALLAGHER	16 May 2024

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.

Chair: John Adams

Vice-chair: Jose de Jesus Munoz Navarro

Treasurer: Tobias Hagedorn

Secretary: Cristian Baigorria

Executive Committee members: Jose de Jesus Munoz Navarro, Cristian Baigorria, Tobias Hagedorn and John Adams

Trustees generally meet every 2 months.

About the Global Alliance for PKU (GAP)

The charity was registered in 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 2024/2025Year

During the last year the organization wasn't able to perform any activities. We did not find a solution to establishing a bank account in Canada, where two trustees reside or any other country where a trustee resides when the Charity is established under UK law. Canadian banking compliance officers declined to approve a bank account in two occasions.

Achievements

Trustees are reviewing options for the future of the Charity and its registration in the UK.

Financial Review

The GAP have no bank accounts, reserve funds and have not spent any funds this year. 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	December 1, 2025	

Charity Commission Annual Return 2025

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 2025.

Financial period

Financial period start date

01/07/2024

Financial period end date

30/06/2025

Income and spending

Income £

£0

Spending £

£0

Number of contracts from government

How many contracts (other than grant agreements) did your charity receive from central government or a local authority during the financial period for this return?

0

Number of grants from government

How many grants did your charity receive from central government or a local authority during the financial period for this return?

0

Income breakdown

Donations and legacies (excluding Endowments Received)

£0

Charitable activities

£0

Other trading activities

£0

Investments

£0

Other

£0

Recipients of grants

Please round all figures to the nearest pound (do not enter decimal points or commas).Individuals

£0

Other charities

£0

Other organisations that are not charities

£0

Trustee payments

Excluding out of pocket expenses, for what were any of the trustees paid during the financial period for this return?

☒ e. None of the trustees have been paid

Did any of the trustees resign and take up employment with your charity in the financial period of this return?

No

Income from outside the UK

Did your charity receive income from outside of the United Kingdom in the financial period of this return?

No

Delivering activities outside the United Kingdom

Did your charity deliver charitable activities outside of the United Kingdom in the financial period of this return?

No

Spending outside of the United Kingdom

Did your charity spend funds outside of the United Kingdom in the financial period of this return?

No

Trading subsidiaries

Does the charity have any trading subsidiaries?

No

Employment contract types

People were permanently employed by your charity

0

People were on fixed-terms contracts with your charity

0

Self-employed people were working for your charity

0

Governance policies

Internal charity financial controls policy and procedures

Yes

Safeguarding policy and procedures

No

Financial reserves policy and procedures

No

Complaints policy and procedures

No

Serious incident reporting policy and procedures

No

Internal risk management policy and procedures

No

Trustee expenses policy and procedures

Yes

Trustee conflicts of interest policy and procedures

Yes

Investing charity funds policy and procedures

Yes

Campaigns and political activity policy and procedures

Yes

Bullying and harassment policy and procedures

Yes

Social media policy and procedures

Yes

Engaging external speakers at charity events policy and procedures

Yes

External risk and impact

Donations,

Not applicable

Other income - grants

Not applicable

Other income - contracts

Not applicable

Other income - investment

Not applicable

Expenditure on charitable activities

Not applicable

Expenditure on overheads

Not applicable

Number of volunteers

Not applicable

Number of employees

Not applicable

Number of trustees

Not applicable

Fundraising activities

Not applicable

Capacity to deliver services

Not applicable

Total service demand

Not applicable

Volunteers

Excluding trustees, provide an estimate of the number of volunteers who carried out charitable activities on behalf of your charity in the United Kingdom during the financial period of this return?

0

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

05/11/2025

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.