



Krabbe UK

Trustees' Annual Report For the year ended 31 March 2022

Objectives and Activities

Charitable Purposes

To relieve sickness and preserve and protect the health of children and adults suffering from Krabbe Disease in the United Kingdom and Europe, in particular but not exclusively by supporting and funding research and promoting the extension of newborn screening for Krabbe Disease.

To preserve and protect the health of the families caring for children and adults suffering from Krabbe Disease in the United Kingdom and Europe by such means as the trustees may determine

To support bereaved families who have lost family members to Krabbe Disease in the United Kingdom and Europe by such means as the charity trustees may determine

Main Activities

We continued to support a number of families who had received a diagnosis of Krabbe Disease and supported others who have children who have Krabbe Disease.

We supported families who lost children to Krabbe Disease during the year and continued to support other families.

We continued to raise awareness of the disease with clinicians and research organisations,, throughout 2021 with video conferences instead of face to face meetings. We were able to attend an in person meeting with Passage Bio, University of Pennsylvania, Orphan Disease Center and University of Manchester in March 2022 to discuss the Gene Therapy Clinical Landscape.

Due to the COVID 19 pandemic, we were unable to hold a Family Support Weekend during 2020. We plan to continue this activity in the future when it is safe to do so.

The charity continued to partner with Great Ormond Street Hospital Children's Charity and Sparks Charity to fund research by Dr Sara Benedetti from University College London entitled Targeting the blood-brain barrier endothelium to increase hematopoietic stem cell engraftment for lysosomal storage disease gene and cell therapy. We also joined GOSH in the 2020/2021 call for research.

We continued to be active participants in The European Reference Network for Inherited Metabolic Disorders (MetabERN) and one of our trustees was a member of the Patient Organisation Steering Committee.

We are members of the United Kingdom LSD Collaborative.

Public Benefit Statement

The Trustees confirm that they have complied with their duty to have due regard to the Charity Commission's guidance on public benefit in exercising their powers and in planning activities for this and future years.

Achievements and Performance

Fundraising has continued at similar levels to previous years, even through the challenging time of the COVID19 pandemic.

Gene Therapy Research continues in the US with Krabbe UK trustees providing advocacy support and information to ensure that this important research continues.

Social Media platforms provided by Krabbe UK continue to be used by families and friends of Krabbe patients to keep in touch, find support and learn more about the disease.

Financial Review

New avenues for raising funds were commenced during the year and a number of supporters engaged in fundraising activities.

The charity has a healthy financial position at the end of the year relative to anticipated expenditure in the next 12 months.

It is expected that our main source of income will be from fund raising activities and donations.

The charity's policy on reserves is to hold the equivalent of 12 months anticipated expenditure.

The Trustees have no concern about the ability of the charity to continue as a going concern.

Structure, Governance and Management

The Charity is a Charitable Incorporated Organisation (a CIO). It was registered in its current legal form on 14 November 2017. The charity was previously an unincorporated association but changed its legal form to a CIO. The assets of the unincorporated association were transferred to the CIO in April 2018. It has a single tier structure and as such the trustees are the members of the charity.

Appointment of trustees

Trustees at the end of the year are parents of children who have lost a child to Krabbe Disease but there is no requirement for trustees to have lost a child. The Trustees can appoint other trustees who have suitable qualifications and interest in Krabbe Disease.

There must be a minimum of three trustees.

Reference and Administrative details

Charity name Krabbe UK

Charity registered in England and Wales 1174472

Charity registered in Scotland Number SC047927

Registered Address 2 Sage Close, Beverley, East Yorkshire HU17 8WH

Current Trustees

Andrew Gibson

Colin Brown

Lindsey Dodds

Declarations

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

Signed on behalf of the charity's trustees.

A handwritten signature in black ink, appearing to read 'Colin R Brown', followed by a long horizontal flourish line.

Colin R Brown

Trustee

30 December 2022

KRABBE UK

RECEIPTS AND PAYMENTS ACCOUNT YEAR ENDED 31 MARCH 2022

RECEIPTS

Donations	1417.15
Just Giving	7271.68
Easy Fundraising	68.29
Facebook Donate	2134.92
Amazon Smile	54.17
Gift Aid	0.00
Bank Interest	45.48

Total income	10991.69
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EXPENDITURE

Marketing	0.00
Family Support	0.00
Insurance	443.30
MetabERN	0.00
Fundraising Materials	108.00
Subscriptions	130.00
Bank Charges	27.60

Total expenditure	708.90
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SURPLUS (DEFICIT)	£10,282.79
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RESERVES

Brought forward - Barclays Account	£79,348.38
Brought forward - Virgin Money Account	£5,577.74
Surplus/deficit for the year	£10,282.79
Carried forward	£95,208.91

Represented by :

Virgin Money Bank Account	£95,208.91
Total Funds Held	£95,208.91

Independent Examiner's Report

I report to the trustees on my examination of the accounts of Krabbe UK ("the Trust") for the year ended 31 / 03 / 2022.

As the charity trustees of the Trust, you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ("the Act").

I report in respect of my examination of the Trust's accounts carried out under section 145 of the 2011 Act and in carrying out my examination, I have followed the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination which gives me cause to believe that in, any material respect:

- accounting records were not kept in accordance with section 130 of the Act or
- the accounts do not accord with the accounting records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in order to enable a proper understanding of the accounts to be reached.

I report on the accounts of the charity for the year ended 31 March 2019 which are set out on pages 4 to 5.



Name: Carrie Coleman

Address: Woodlea, Swan Avenue, Kennoway, Fife

Date 30 December 2022