

Trustees' Annual Report

From 1st April 2023 - To 31st March 2024

Charity name: Nicolaides-Baraitser Syndrome (NCBRS) Worldwide Foundation

Charity registration number: 1190194

Objectives and Activities

Summary of the purposes of the charity as set out in its governing document:

The relief of sickness and the preservation and protection of good health of persons suffering from Nicolaides Baraitser Syndrome worldwide through the provision of support, education, practical advice, annual conferences, welcome packages, small grants and the funding of research studies into Nicolaides Baraitser Syndrome, the useful results of which will be published for the public benefit.

Summary of the main activities in relation to those purposes for the public benefit, in particular, the activities, projects or services identified in the accounts:

Supporting families:

- We hold regular Zoom meetings for affected families, carers of NCBRS as well as medical professionals on topics of interest to the group.
- We send welcome packs to families.
- We provide support through our Facebook group, answering questions and providing information as needed.
- We make grants based on our grant policy to help provide necessary equipment and support.
- We make connections between families (with their permission) so more local support can be provided on a country level.

We promote awareness of NCBRS:

- We keep our website and social media up to date with information.
- We provide regular newsletters to stakeholders who sign up for updates from our website
- We connect with other organisations that benefit the people living with NCBRS.
- We attend conferences and meetings to raise awareness about NCBRS.
- We join and collaborate with other rare disease organisations Gene People UK, Beacon for Rare Diseases, Rare Disease International, Rare Revolution Magazine, Healthinote, Rare Patient Voice, Patient Worthy and Global Genes so that we can broaden the platform and audience that can learn about NCBRS.

We advocate for research into NCBRS

- We set up a patient registry to promote research.

- We collaborate with academic organisations and hospitals in the conduct of studies on NCBRS.
- We monitor publications on NCBRS to look for new research collaborations
- We have established a Scientific Advisory Board for the Foundation.

Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit:

The Trustees are always mindful of the guidance issued by the Charity Commission on public benefit and discharge these responsibilities by holding regular talks within our trustees' quarterly meetings.

Additional information

Policy on grantmaking:

We make grants when it will assist our patients affected by NCBRS and their families and/or promote medical research into NCBRS. A formal grant policy is in place with clear guidelines.

Contributions made by volunteers:

The Trustees, as unpaid volunteers, recognise the input of all our volunteers (seven on 31st March 2024 including the six trustees) The CIO is entirely dependent on all its volunteers to effectively run the CIO. We operate with no paid staff.

Achievements and Performance

Summary of the main achievements of the charity, identifying the difference the charity's work has made to the circumstances of its beneficiaries and any wider benefits to society as a whole:

Family Support

- All of our activities are still currently held virtually. We aim to hold Zoom conferences at least every 2 months or more for affected families worldwide, in which doctors - geneticists in the field speak, do presentations and answer questions from families.
- We answer individual queries from group members to support them in their journey.
- We are supporting just under 300 families who have a child/family member diagnosed with NCBRS.
- Global NCBRS Awareness Day is on the 9th of October when people worldwide come together to help spread awareness of NCBRS. We have had a group of families in Germany meet up for the weekend to connect and share experiences with one another. A UK family meeting is in the planning for mid-2024 and we are also in the planning stages for a USA conference in 2025.
- We received two requests for grants for funds for support equipment this year, which was reviewed and approved by the Board.

Research

- Our global NCBRS Patient Registry has grown, and we are starting to see a lot more people being diagnosed with the condition and taking part in the registry. We have collaborated with other Rare Disease organisations to further our work and gain skills. We are supporting just fewer than 300 families whose child has a diagnosis of NCBRS.
- A number of new research studies are now in the set up phase:

1. **Objective:** To look at the genetic basis of the condition
Summary: Analysis based on data in the registry – which deletions cause the most severe disease, which are the most common and how this links to the symptoms of the syndrome.
Status: This is currently on hold while the researcher is looking for funding and ethics approval
 2. **Objective:** To look at the progression of NCBRS in adult patients
Summary: To map out the characteristics of the syndrome in patients over 18 in order to help guide the management of the syndrome in younger patients through earlier awareness and monitoring for potential issues. The study will be published (with anonymised data) to help raise awareness among physicians.
Status: Ongoing. Expected to complete recruitment of participants June 2023
 3. **Objective:** Facematch - using facial recognition features and Artificial Intelligence to help diagnose NCBRS at an earlier stage
Summary: NCBRS patients have distinct facial features and similarities. Patients/Carers are encouraged to take part and share photos and clinical information in order to train and test the algorithm used to diagnose NCBRS.
Status: Ongoing
- A key objective in order to encourage more research and to monitor ongoing research is the establishment of our Scientific Advisory Board, which was formed in late 2023.

The purpose of the SAB is to:

- Provide advice to the NCBRS Worldwide Foundation's Board of Trustees on scientific and clinical matters for the purposes of the NCBRS Worldwide Foundation's work and collaborations with stakeholders,
- Consider research/study requests received by the NCBRS Worldwide Foundation and provide guidance to the Board of Trustees,
- Suggest potential research and help the Foundation get connections within the research community,
- Contribute to the ongoing development of the NCBRS Worldwide Foundation for the benefit of the global patient community.

Awareness

- A campaign was conducted around the 9th of October 2023 for NCBRS Awareness Day as well as an awareness campaign around Rare Disease Day on the 29th of February 2024 and the Dazzle4Rare campaign in August.
- Regular Newsletters were sent to all stakeholders that signed up for updates through our website.
- Updates were made to the website to improve access to information on NCBRS.
- Awareness of NCBRS was made by attendance at conferences such as the Orphan Drug Conference in Barcelona in Oct 2023

Financial Review

Review of the charity's financial position at the end of the period:

From the continued support in donations from our families, the general public globally and sales from the NCBRS apparel, the trustees can report that we are in a stronger financial position from the start of the year. This will enable us to continue our objectives to help the NCBRS community.

Bank and cash reserves on 31 March 2024 were £1,000, the same position as at the beginning of the financial period (1st April 2023).

Statement explaining the policy for holding reserves stating why they are held:

Reserves comprise entirely of Bank and cash funds, these are held to facilitate our future operational costs for one year.

Amount of reserves held: £1,000

There are no uncertainties about the charity continuing as a going concern.

Additional information

The charity's principal sources of funds (including any fundraising):

Donations - the primary source is Facebook and JustGiving which includes donations and fundraisers and Paypal donations. We've had several families hold fundraisers in aid of the Foundation, with which the funds were donated to us. The Foundation held a 5K Walk fundraiser virtually. One fundraiser is aiming to raise 10K by climbing Mount Kilimanjaro. We are also partnered with EasyFundraising and Don't Send Me A Card, which all generate donations to the Foundation.

Investment policy and objectives including any social investment policy adopted:

We aim to generate sufficient funds for our current and future activities. We also invest in our website, Zoom conferencing and awareness materials at present.

Description of the principal risks facing the charity:

The risks are limited to an inability to continue to generate funds to continue our objectives.

Structure, Governance and Management

Type of governing document:

Charitable Incorporated Organisation whose only voting members are its charity trustees.

How is the charity constituted?

CIO

Trustee selection methods including details of any constitutional provisions e.g. election to post or name of any person or body entitled to appoint one or more trustees:

Apart from the first charity trustees, every trustee must be appointed for a term of three years by a resolution passed at a properly convened meeting of the charity trustees. In selecting individuals for appointment as charity trustees, the charity trustees must have regard to the skills, knowledge and experience needed for the effective administration of the CIO.

Additional information

Policies and procedures adopted for the induction and training of trustees:

Our Co-Founder has completed a one year mentoring program through Beacon for Rare Disease mentoring program to gain skills in various areas to support the organisation's running and to streamline our processes.

Reference and Administrative details

Charity name:

Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation

Other names the charity uses:

**NCBRS Worldwide Foundation
NCBRS Parent Support**

Registered charity number:

1190194

Charity's principal address:

**124 City Road
London
EC1V 2NX
United Kingdom**

Names of the charity trustees who manage the charity:

<u>Name</u>	<u>Position</u>	<u>Date appointed:</u> <small>(if not whole year)</small>
1. Lee Reavey	CEO	
2. Nuala Ryan	Chair	
3. Shabnam Khademian	Trustee	
4. Christine Mutena	Trustee	
5. Dr Chui Fung Chong	Trustee	
6. Jenny Brown	Trustee	

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):

Nuala Ryan

Lee Reavey

Position:

Chair of Trustees

CEO



Date:

14 Apr 2023

14 Apr 2023



NCBSRS
WORLDWIDE
FOUNDATION

 CHARITY COMMISSION FOR ENGLAND AND WALES  NCBRS WORLDWIDE FOUNDATION NICOLAIDES-BARAITSER SYNDROME ALONE WE'RE RARE. TOGETHER WE ARE STRONG	Charity Name		No (if any)		CC16a
	Nicolaidēs Baraitser Syndrome (NCBRS) Worldwide Foundation		1190194		
	Receipts and payments accounts				
For the period from	Period start date	To	Period end date		
	01-04-2023		31-03-2024		

Section A Receipts and payments



	Unrestricted funds	Restricted funds	Endowment funds	Total funds	Last year
	to the nearest £	to the nearest £	to the nearest £	to the nearest £	to the nearest £
A1 Receipts					
Donations	1,184	-	-	1,184	5,205
AmazonSmile & EasyFundraising	63	-	-	63	129
Merchandise - Redbubble - Profit	66	-	-	66	3
Fundraisers by Foundation	755	-	-	755	1,118
Fundraisers by Others	5,932	-	-	5,932	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	8,000	-	-	8,000	6,454
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,000	-	-	8,000	6,454
A3 Payments					
Operational Costs	460	-	-	460	870
Postage, Packaging, Stationery	97	-	-	97	77
Advertsing/Awareness	126	-	-	126	202
Grants Paid	989	-	-	989	-
Sub total	1,672	-	-	1,672	1,149
Total payments	1,672	-	-	1,672	1,149
Net of receipts/(payments)	6,328	-	-	6,328	5,305
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	21,467	-	-	21,467	-
Cash funds this year end	27,795	-	-	27,795	5,305

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B1 Cash funds	Bank	27,795	-	-
	Cash	-	-	-
	Total cash funds	27,795	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
B3 Investment assets			-	-
			-	-
	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)

B4 Assets retained for the charity's own use			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
B5 Liabilities			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		Lee Reavey	14-04-24
		Nuala Ryan	14-04-24