

Trustees' Annual Report

From 1st April 2024 - To 31st March 2025

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:

To support 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 send welcome packs to families to help them get started.
- We developed a Patient Information Leaflet to support families dealing with a new diagnosis of NCBRS, to help them understand what this means
- We bring individual family cases to the Scientific Advisory Board for advice, as appropriate and as approved by families, to help understand particular issues they face.
- We provide support through our Facebook group, where we answer questions and share information as needed.
- We offer grants based on our grant policy to help provide necessary equipment and support for families.
- With permission, we connect families to facilitate local support on a country level.
- In June 2024, we held our first family conference in the UK, which was attended by over 60 people, including specialists and experts in NCBRS from nine countries.

Promoting Awareness of NCBRS:

- We maintain an updated website and social media presence to disseminate relevant information effectively. Additionally, we distribute regular newsletters to stakeholders who subscribe to updates through our website.
- We actively collaborate with other organisations that support individuals living with NCBRS and participate in conferences and meetings to enhance awareness of this condition.
- Furthermore, we engage with various rare disease organisations, including Gene People UK, Beacon for Rare Diseases, Rare Disease International,

Rare Revolution Magazine, Rare Patient Voice, and Global Genes, to broaden our platform and reach a wider audience regarding NCBRS.

We advocate for research into NCBRS

- To facilitate this, we have established a patient registry aimed at promoting research initiatives. We engage in collaborative efforts with academic institutions and hospitals to conduct comprehensive studies on NCBRS, while also diligently monitoring relevant publications to identify opportunities for new research collaborations.
- Moreover, we have constituted a Scientific Advisory Board (SAB) to guide the Foundation's research initiatives. The SAB is actively engaged in advancing research related to NCBRS and has presented a poster at the BPNA Conference in January 2025, titled "Genotype-Phenotype Correlations in a Large Cohort of Patients with Nicolaides-Baraitser Syndrome (NCBRS)."
- In addition, the SAB has initiated the establishment of a biobank collection to further support and enhance our research efforts.
- The foundation collaborated with Prof Dagmar Wiczorek at the University of Düsseldorf to assess the progression of NCBRS in adult patients.

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 and SAB Members, as unpaid volunteers, recognise the input of all our volunteers (thirteen on 31st March 2025, including the five 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

- Our organisation conducts various activities, many of which are held in a virtual format. We provide responses to individual inquiries from group members to aid them in their respective journeys. To date, we are supporting over 315 families who have a child or family member diagnosed with NCBRS.

- Global NCBRS Awareness Day is observed on October 9th each year, when individuals around the world unite to promote awareness of NCBRS. In June 2024, we hosted a family meeting in the UK, which was attended by more than 60 participants, including specialists and experts in NCBRS from nine countries. Furthermore, we are currently in the planning stages for a conference in the United States scheduled for 2025.

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 over 315 families who have a child/family member diagnosed with 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: Recruitment Complete. Publication is being generated at present based on the results. Projected date of publication: April 2025.
 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 2024 for NCBRS Awareness Day, as well as an awareness campaign around Rare Disease Day on the 28th of February 2025 and the Dazzle4Rare campaign in August 2024.
- Regular Newsletters are sent to all stakeholders who have signed up for updates through our website.
- Updates were made to the website to improve access to information on NCBRS.
- Awareness of NCBRS was raised by attendance at various conferences/meetings from various Trustees and SAB members.

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 than at 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 2025 were £1,000, the same position as at the beginning of the financial period (1st April 2024).

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

Reserves comprise entirely of Bank and cash funds, which 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 are primarily collected through our website, Facebook, and JustGiving, which include direct contributions and fundraisers, as well as donations via PayPal. Several families have organised fundraisers in support of the Foundation, with notable success. One fundraiser raised over £10,000 through a climb of Mount Kilimanjaro, and this year, they are currently raising funds for an expedition to Everest Base Camp. Additionally, we are partnered with EasyFundraising and Don't Send Me A Card, both of which generate donations for the Foundation.

Investment policy and objectives including any social investment policy adopted:

We seek to raise adequate funds for our ongoing and upcoming endeavours. Currently, we are also allocating resources to our website, in-person events and promotional materials.

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 still attends various trainings/webinars 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. Christine Mutena	Trustee	
4. Dr Chui Fung Chong	Trustee	
5. 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):

Nuala A. Ryan

Lee Reavey

Full Name(s):

Nuala Ryan

Lee Reavey

Position:

Chair of Trustees



CEO

Date:

07 May 2025

07 May 2025

NCBRS
WORLDWIDE
FOUNDATION

 CHARITY COMMISSION FOR ENGLAND AND WALES  NCBRS WORLDWIDE FOUNDATION NICOLAIDES-BARAITSER SYNDROME <small>ALONE WE'RE RARE. TOGETHER WE ARE STRONG</small>	Charity Name		No (if any)		CC16a
	Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation		1190194		
	Receipts and payments accounts				
	For the period from	Period start date	To	Period end date	
	01-04-2024		31-03-2025		

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	10,789	-	-	10,789	1,184
AmazonSmile & EasyFundraising	16	-	-	16	63
Merchandise - Redbubble - Profit	-	-	-	-	66
Fundraisers by Foundation	-	-	-	-	755
Fundraisers by Others	6,262	-	-	6,262	5,932
Sub total (Gross income for AR)	17,067	-	-	17,067	8,000
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	17,067	-	-	17,067	8,000
A3 Payments					
Operational Costs	1,420	-	-	1,420	460
Postage, Packaging, Stationery	66	-	-	66	97
Advertising/Awareness	4,753	-	-	4,753	126
Grants Paid	-	-	-	-	989
Subscription/Training	109	-	-	109	
UK Event	6,298	-	-	6,298	
Sub total	12,646	-	-	12,646	1,672
Total payments	12,646	-	-	12,646	1,672
Net of receipts/(payments)	4,420	-	-	4,420	6,328
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	27,795	-	-	27,795	-
Cash funds this year end	32,216	-	-	32,216	6,328

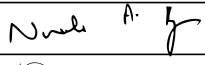

Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
B1 Cash funds	Bank	32,216	-	-
	Cash	-	-	-
	Total cash funds	32,216	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		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
		Nuala Ryan	07 May 2025
		Lee Reavey	07 May 2025