



CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report for the period

From **30th June 2020** (Period start date) - To **31st March 2021** (Period end date)

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

Charity registration number: **1190194**

Objectives and Activities

	SORP reference	
Summary of the purposes of the charity as set out in its governing document	Para 1.17	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.	Para 1.17 and 1.19	We hold meetings for affected families of NCBRS. We keep our website and social media up to date with information. We connect with other organisations that benefit the people living with NCBRS. We send welcome packs to families. We make grants. We will advocate for research into NCBRS
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	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 (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	We make grants when it will assist our patients affected by NCBRS and their families and/or to promote medical research into NCBRS.
Policy on social investment including program related investment	Para 1.38	The trustees have invested in our website and zoom conferencing.
Contribution made by volunteers	Para 1.38	The Trustees, as unpaid volunteers, recognise the input of all our volunteers (6 at 31st March 2021 including the 3 trustees) The CIO is entirely dependant on all its volunteers to effectively run the CIO. We operate with no paid staff.
Other		

Achievements and Performance

	SORP reference	
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.	Para 1.20	Due to the ongoing coronavirus pandemic we're unable to hold our usual face-to-face conference/s (two cancelled in 2020) so all of our activities are held virtually at the moment. We've held several Zoom conferences at least every 2 months or more for affected families worldwide, of which we've had doctors/geneticists in the field speaking at the events. We created an online shop where people can purchase NCBRS apparel. We held our first ever worldwide awareness day on 9th October 2020. We have partnered with Rare Disease International and Rare Disease Day to further spread awareness of NCBRS. We have partnered with the Coordination of Rare Diseases at Sanford (CoRDS) to create and establish a patient registry. We have partnered with FaceMatch to see whether facial recognition technology can determine a diagnosis of NCBRS. We have created our welcome packs to send to new and existing families. We have completely revamped our website and logos.

Additional information (optional)

You may choose to include further statements where relevant about:

Achievements against objectives set	Para 1.41	
Performance of fundraising activities against objectives set	Para 1.41	
Investment performance against objectives	Para 1.41	
Other		

Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	<p>Following our first awareness day's success and the continued support in donations from our families and the general public globally and sales from the NCBRS apparel, the trustees, can report that we are in a strong financial position from when we became a charity in June 2020. This will enable us to continue our objectives to help the NCBRS community.</p> <p>Bank and cash reserves at 31 March 2021 were £1,000, £1,000 up on the position at the beginning of the financial period (30th June 2020 - Usually 1st April each year).</p>
Statement explaining the policy for holding reserves stating why they are held	Para 1.22	Reserves comprise entirely of Bank and cash funds, these are held to facilitate our future operational costs for two years.
Amount of reserves held	Para 1.22	£1,000
Reasons for holding zero reserves	Para 1.22	N/A
Details of fund materially in deficit	Para 1.24	N/A
Explanation of any uncertainties about the charity continuing as a going concern	Para 1.23	There are no uncertainties.

Additional information (optional)

You may choose to include further statements where relevant about:

The charity's principal sources of funds (including any fundraising)	Para 1.47	<p>Donations - the primary source is Facebook Fundraisers and our Paypal donate. We had a family hold a fundraising run in aid of the awareness day in October 2020 in Ireland, with which the funds were donated to the Foundation. We had another person hold a 12 hour online gaming stream, again with which the funds were donated to the Foundation.</p> <p>We are also partnered with AmazonSmile and EasyFundraising.</p>
Investment policy and objectives including any social investment policy adopted	Para 1.46	<p>We aim to generate sufficient funds for our current and future activities. We also invest in our website and zoom conferencing at present.</p>
A description of the principal risks facing the charity	Para 1.46	<p>The risks are limited to an inability to continue to generate funds to continue our objectives.</p>
Other		

Structure, Governance and Management

Description of charity's trusts:		
Type of governing document (trust deed, royal charter)	Para 1.25	Charitable Incorporated Organisation whose only voting members are its charity trustees.
How is the charity constituted? (e.g. unincorporated association, CIO)	Para 1.25	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	Para 1.25	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 (optional)

You may choose to include further statements where relevant about:

Policies and procedures adopted for the induction and training of trustees	Para 1.51	
The charity's organisational structure and any wider network with which the charity works	Para 1.51	
Relationship with any related parties	Para 1.51	
Other		

Reference and Administrative details

Charity name	Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation
Other name the charity uses	NCBRS Worldwide Foundation NCBRS Parent Support
Registered charity number	1190194
Charity's principal address	Kemp House 152-160 City Road London EC1V 2NX United Kingdom

Names of the charity trustees who manage the charity

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Lee Reavey	CEO		
2	Helen Robinson	Chair		
3	Michelle Reavey	Trustee		

Corporate trustees – names of the directors at the date the report was approved

Director name		
N/A		

Name of trustees holding title to property belonging to the charity

Trustee name	Dates acted if not for whole year	
N/A		

Funds held as custodian trustees on behalf of others

Description of the assets held in this capacity	N/A
Name and objects of the charity on whose behalf the assets are held and how this falls within the custodian charity's objects	
Details of arrangements for safe custody and segregation of such assets from the charity's own assets	

Additional information (optional)

Names and addresses of advisers (Optional information)

Type of adviser	Name	Address
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Name of chief executive or names of senior staff members (Optional information)

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Exemptions from disclosure

Reason for non-disclosure of key personnel details

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Other optional information

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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)

Lee Reavey

Helen Robinson

Position (eg
Secretary, Chair, etc)

Trustee

Chair

Date

01-04-2021




Charity Name				No (if any)		CC16a	
Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation				1190194			
Receipts and payments accounts							
For the period from		Period start date		Period end date			
		30-06-2020		To		31-03-2021	

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	13,020	-	-	13,020	-
AmazonSmile & EasyFundraising	56	-	-	56	-
Merchandise - Redbubble - Profit	271	-	-	271	-
Sub total (Gross income for AR)	13,348	-	-	13,348	-
A2 Asset and investment sales, (see table).					
	- 0	- 0	- 0	-	- 0
Sub total	- 0	- 0	- 0	-	- 0
Total receipts	13,348	- 0	- 0	13,348	- 0
A3 Payments					
Operational Costs	298	-	-	298	-
Postage, Packaging, Stationery	180	-	-	180	-
Welcome Packs	398	-	-	398	-
Awareness Products (Lanyard & Wristband)	395	-	-	395	-
Sub total	1,271	-	-	1,271	-
A4 Asset and investment purchases, (see table)					
	- 0	- 0	- 0	-	- 0
Sub total	- 0	- 0	- 0	-	- 0
Total payments	1,271	- 0	- 0	1,271	- 0
Net of receipts/(payments)	12,077	-	-	12,077	-
A5 Transfers between funds	- 0	-	-	-	-
A6 Cash funds last year end	- 0	-	-	-	-
Cash funds this year end	12,077	-	-	12,077	-

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	12,062	-	-
	Petty Cash	15	-	-
		-	-	-
	Total cash funds	12,077	-	-
	(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
		Lee Reavey		01-04-2021
	H.V. Robinson	Helen Robinson		01-04-2021