

## Trustees' Annual Report for the period

From **1st April 2021** (Period start date) - To **31st March 2022** (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	<b>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.</b>
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	<p><b><u>Supporting families:</u></b></p> <ul style="list-style-type: none"> <li>• <b>We hold regular zoom meetings for affected families, carers of NCBRS as well as medical professionals on topics of interest to the group.</b></li> <li>• <b>We send welcome packs to families</b>            - We provide support through our facebook group, answering questions and providing information as needed.</li> <li>• <b>We make grants based on our grants policy to help provide necessary equipment and support.</b></li> </ul> <p><b><u>We promote awareness of NCBRS</u></b></p> <ul style="list-style-type: none"> <li>• <b>We keep our website and social media up to date with information.</b></li> <li>• <b>We connect with other organisations that benefit the people living with NCBRS.</b></li> <li>• <b>We attend conferences to raise awareness about NCBRS</b></li> </ul>

		<u>We advocate for research into NCBRS</u> <ul style="list-style-type: none"> <li>• We set up a patient registry to promote research</li> <li>• We collaborate with academic organisations and hospitals in conduct of studies on NCBRS</li> </ul>
Statement confirming whether the trustees have had regard to the guidance issued by the Charity Commission on public benefit	Para 1.18	<b>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.</b>

### Additional information (optional)

You may choose to include further statements where relevant about:

	SORP reference	
Policy on grant making	Para 1.38	<b>We make grants when it will assist our patients affected by NCBRS and their families and/or to promote medical research into NCBRS.</b>
Policy on social investment including program related investment	Para 1.38	
Contribution made by volunteers	Para 1.38	<b>The Trustees, as unpaid volunteers, recognise the input of all our volunteers (six on 31st March 2022 including the three trustees) The CIO is entirely dependent on all its volunteers to effectively run the CIO. We operate with no paid staff.</b>
Other		

## 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.	Para 1.20	<p>Due to the continued ongoing coronavirus pandemic we are still unable to hold our usual face-to-face conference/s. All of our activities are still currently held virtually. We hold Zoom conferences at least every 2 months or more for affected families worldwide, of which doctors - geneticists in the field speak, do presentations and answer questions. Global NCBRS Awareness day on 9th October 2020, where people around the world came together to help spread awareness of NCBRS. We had a group of four families in England meet up for the day to connect and share experiences with one another.</p> <p>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 220 families whose child has a diagnosis of NCBRS.</p> <p>A number of new research studies are now in the set up phase:</p> <ol style="list-style-type: none"> <li>1. To look at the genetic basis of the condition – which deletions cause the most severe disease, which are the most common and how this links to the symptoms of the syndrome.</li> <li>2. To look at progression of NCBRS in adults.</li> </ol>
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### 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		
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## Financial Review

Review of the charity's financial position at the end of the period	Para 1.21	<p>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.</p> <p>Bank and cash reserves on 31 March 2022 were £1,000, the same position at the beginning of the financial period (1st April 2021).</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 one year.
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've had several families hold fundraisers in aid of the Foundation, with which the funds were donated to us. The Foundation held two fundraisers, a 5K Walk and a Fitness FUNdrasie, both virtually. We are also partnered with AmazonSmile, EasyFundraising and Don't Send Me A Card, which all generates donations to the Foundation.</p>
Investment policy and objectives including any social investment policy adopted	Para 1.46	We aim to generate sufficient funds for our current and future activities. We also

		invest in our website and zoom conferencing at present.
A description of the principal risks facing the charity	Para 1.46	The risks are limited to an inability to continue to generate funds to continue our objectives.

## 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	Our Co-Founder is on a training course to gain skills in recruiting further trustees to our board.
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	<b>Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation</b>
Other names the charity uses	<b>NCBRS Worldwide Foundation NCBRS Parent Support</b>
Registered charity number	<b>1190194</b>
Charity's principal address	<b>124 City Road London EC1V 2NX United Kingdom</b>

## 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 a trustee (if any)
1	<b>Lee Reavey</b>	<b>CEO</b>		
2	<b>Helen Robinson</b>	<b>Chair</b>		
3	<b>Michelle Reavey</b>	<b>Trustee</b>		

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

Director name		
<b>N/A</b>		

Name of trustees holding title to property belonging to the charity:

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

## 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)

	
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Full name(s)

Lee Reavey	
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Position (eg  
Secretary, Chair, etc)

Trustee	
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Date

04-04-2022
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 <b>CHARITY COMMISSION</b> FOR ENGLAND AND WALES	Charity Name		No (if any)		<b>CC16a</b>
	Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation		1190194		
	<b>Receipts and payments accounts</b>				
 <b>NCBRS WORLDWIDE FOUNDATION</b> NICOLAIDES-BARAITSER SYNDROME <small>ALONE WE'RE RARE. TOGETHER WE ARE STRONG</small>	For the period from	Period start date	To	Period end date	
		01-04-2021		31-03-2022	

## 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 £
<b>A1 Receipts</b>					
Donations	6,278	-	-	6,278	13,020
AmazonSmile & EasyFundraising	105	-	-	105	56
Merchandise - Redbubble - Profit	59	-	-	59	271
Fundraisers by Foundation	2,244	-	-	2,244	-
<b>Sub total (Gross income for AR)</b>	<b>8,686</b>	<b>-</b>	<b>-</b>	<b>8,686</b>	<b>13,348</b>
<b>A2 Asset and investment sales, (see table).</b>					
	-	-	-	-	-
<b>Sub total</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>Total receipts</b>	<b>8,686</b>	<b>-</b>	<b>-</b>	<b>8,686</b>	<b>13,348</b>
<b>A3 Payments</b>					
Operational Costs	857	-	-	857	298
Postage, Packaging, Stationery	176	-	-	176	180
Advertsing/Awareness	137	-	-	137	-
Grants Paid	3,431	-	-	3,431	-
Welcome Packs	-	-	-	-	398
Awareness Products (Lanyard & Wristband)	-	-	-	-	395
<b>Sub total</b>	<b>4,601</b>	<b>-</b>	<b>-</b>	<b>4,601</b>	<b>1,271</b>
<b>Total payments</b>	<b>4,601</b>	<b>-</b>	<b>-</b>	<b>4,601</b>	<b>1,271</b>
<b>Net of receipts/(payments)</b>	<b>4,085</b>	<b>-</b>	<b>-</b>	<b>4,085</b>	<b>12,077</b>
<b>A5 Transfers between funds</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>	<b>-</b>
<b>A6 Cash funds last year end</b>	<b>12,077</b>	<b>-</b>	<b>-</b>	<b>12,077</b>	<b>-</b>
<b>Cash funds this year end</b>	<b>16,162</b>	<b>-</b>	<b>-</b>	<b>16,162</b>	<b>12,077</b>


## 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 £
<b>B1 Cash funds</b>	Bank	16,138	-	-
	Cash	23	-	-
	<b>Total cash funds</b>	<b>16,162</b>	<b>-</b>	<b>-</b>
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds	Restricted funds	Endowment funds
		to nearest £	to nearest £	to nearest £
<b>B2 Other monetary assets</b>		-	-	-
		-	-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B3 Investment assets</b>			-	-
			-	-

	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
<b>B4 Assets retained for the charity's own use</b>			-	-
			-	-

	Details	Fund to which liability relates	Amount due (optional)	When due (optional)
<b>B5 Liabilities</b>			-	
			-	

Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval
		<b>Lee Reavey</b>	<b>04-04-22</b>