NICOLAIDES BARAITSER SYNDROME (NCBRS) WORLDWIDE FOUNDATION

England & Wales · Charity number 1190194

Details

Other names	NCBRS PARENT SUPPORT, NCBRS WORLDWIDE FOUNDATION
Status	Registered
Legal form	CIO
Registered	2020-06-30
Register	View on the Charity Commission register

Contact

Address

NCBRS Worldwide Foundation
124 City Road
London
EC1V 2NX

Phone	01582655702
Email	contactus@ncbrs.com
Website	www.ncbrs.com

Activities

Objects: 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 BENE?T.

Activities: SUPPORT, EDUCATION, PRACTICAL ADVICE, ANNUAL CONFERENCES, WELCOME PACKAGES, SMALL GRANTS

Classification

- **How:** Makes Grants To Individuals, Provides Other Finance, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** General Charitable Purposes, Disability
- **Who:** Children/young People, People With Disabilities, Other Defined Groups

Geography

- Australia
- Canada
- France
- Ireland
- Isle Of Man
- Italy
- Northern Ireland
- Scotland
- Spain
- United States
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£17,067	£12,646	-	-
2024-03-31	£8,000	£1,672	-	-
2023-03-31	£6,454	£1,149	-	-
2022-03-31	£8,686	£4,601	-	-
2021-03-31	£13,348	£1,271	-	-

Trustees

Name	Role	Appointed
Nuala Ryan	Chair	2022-04-01
Christine Mutena		2022-10-24
Dr Chui Fung Chong Ms		2022-11-07
Lee Craig Reavey		2020-06-01

Accounts

NCBRS WORLDWIDE FOUNDATION
NICOLAIDES-BARAITSER SYNDROME
ALONE WE'RE RARE, TOGETHER WE ARE STRONG

CHARITY COMMISSION
FOR ENGLAND AND WALES

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 NCBR, 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 Wieczorek 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:

	Name	Position	Date appointed: (if not whole year)
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):

Full Name(s):	Nuala Ryan	Lee Reavey
Position:	Chair of Trustees	CEO
Date:	07 May 2025	07 May 2025

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)
Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation	1190194

Receipts and payments accounts

CC16a

For the period from	Period start date	To	Period end date
	01-04-2024		31-03-2025

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year 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 to nearest £	Restricted funds to nearest £	Endowment funds 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

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds 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

Accounts

NCBRS WORLDWIDE FOUNDATION
NICOLAIDES-BARAITSER SYNDROME
ALONE WE'RE RARE, TOGETHER WE ARE **STRONG**

CHARITY COMMISSION
FOR ENGLAND AND WALES

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:

	Name	Position	Date appointed: (if not whole year)
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):	Nuala A.	
Full Name(s):	Nuala Ryan	Lee Reavey
Position:	Chair of Trustees	CEO
Date:	14 Apr 2023	14 Apr 2023

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)
Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation	1190194

Receipts and payments accounts

CC16a

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
Advertising/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 A.	Nuala Ryan	14-04-24

Accounts

NCBRS WORLDWIDE FOUNDATION
NICOLAIDES-BARAITSER SYNDROME
ALONE WE'RE RARE, TOGETHER WE ARE **STRONG**

CHARITY COMMISSION
FOR ENGLAND AND WALES

Trustees' Annual Report

From 1st April 2022 **- To** 31st March 2023

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 prepared the documentation needed for setting up of 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 (eight on 31st March 2023 including the seven 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 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. Other family meetings are in the planning stage for US and Canada
- We had one request for a grant 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 setup of a Scientific Advisory Board. Documentation has been prepared in relation to the Objectives, roles and responsibilities of the Board and it is planned to advertise for members of the Board in the next 3-6 months.

Awareness

- A campaign was conducted around the 9th of October 2022 for NCBRS Awareness Day as well as an awareness campaign around Rare Disease Day on the 28th of February 2023.
- 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.

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 2023 were £1,000, the same position as at the beginning of the financial period (1st April 2022).

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. We are also partnered with AmazonSmile (now closed), 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 and Zoom conferencing 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 completed a training course to gain skills in recruiting further trustees to our board. We are pleased to say we recruited a further four trustees in 2022 to help Foundation achieve its purposes.

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:

	Name	Position	Date appointed: (if not whole year)
1.	Lee Reavey	CEO	
2.	Nuala Ryan	Chair	
3.	Lara Pastura	Trustee	
4.	Shabnam Khademian	Trustee	24 October 2022
5.	Christine Mutena	Trustee	24 October 2022
6.	Dr Chui Fung Chong	Trustee	07 November 2022
7.	Jenny Brown	Trustee	07 November 2022

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:	24 Apr 2023	24 Apr 2023

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)	
Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation	1190194	CC16a

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01-04-2022		31-03-2023

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
Donations	5,205	-	-	5,205	6,278
AmazonSmile & EasyFundraising	129	-	-	129	105
Merchandise - Redbubble - Profit	3	-	-	3	59
Fundraisers by Foundation	1,118	-	-	1,118	2,244
Sub total*(Gross income for AR)*	6,454	-	-	6,454	8,686
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	6,454	-	-	6,454	8,686
A3 Payments					
Operational Costs	870	-	-	870	857
Postage, Packaging, Stationery	77	-	-	77	176
Advertising/Awareness	202	-	-	202	137
Grants Paid	-	-	-	-	3,431
Sub total	1,149	-	-	1,149	4,601
Total payments	1,149	-	-	1,149	4,601
Net of receipts/(payments)	5,305	-	-	5,305	4,085
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	16,162	-	-	16,162	-
Cash funds this year end	21,467	-	-	21,467	4,085

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	**Bank**	21,467	-	-
	Cash	-	-	-
	Total cash funds	21,467	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds 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	25-04-23

Accounts

NCBRS WORLDWIDE FOUNDATION
NICOLAIDES-BARAITSER SYNDROME
ALONE WE'RE RARE, TOGETHER WE ARE **STRONG**

CHARITY COMMISSION
FOR ENGLAND AND WALES

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	**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	**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 grants policy to help provide necessary equipment and support.** **We promote awareness 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 attend conferences to raise awareness 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 conduct of studies on 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	
Contribution made by volunteers	Para 1.38	**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.**
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	**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.** **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.** **A number of new research studies are now in the set up phase:** **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.** **2. To look at progression of NCBRS in adults.**

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	**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 2022 were £1,000, the same position at the beginning of the financial period (1st April 2021).**
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	**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.**
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	**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

	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	**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

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

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Other optional information

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	
Position (eg Secretary, Chair, etc)	Trustee	
Date	04-04-2022	

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)	
Nicolaides Baraitser Syndrome (NCBRS) Worldwide Foundation			1190194	CC16a

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	01-04-2021		31-03-2022

Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £	Last year to the nearest £
A1 Receipts					
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	-
Sub total*(Gross income for AR)*	8,686	-	-	8,686	13,348
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	8,686	-	-	8,686	13,348
A3 Payments					
Operational Costs	857	-	-	857	298
Postage, Packaging, Stationery	176	-	-	176	180
Advertising/Awareness	137	-	-	137	-
Grants Paid	3,431	-	-	3,431	-
Welcome Packs	-	-	-	-	398
Awareness Products (Lanyard & Wristband)	-	-	-	-	395
Sub total	4,601	-	-	4,601	1,271
Total payments	4,601	-	-	4,601	1,271
Net of receipts/(payments)	4,085	-	-	4,085	12,077
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	12,077	-	-	12,077	-
Cash funds this year end	16,162	-	-	16,162	12,077

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

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B1 Cash funds	**Bank**	16,138	-	-
	Cash	23	-	-
	Total cash funds	16,162	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-

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 asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-

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

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

Accounts

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 weather 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	**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.** **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).**
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	**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 where donated to the Foundation. We had another person hold a 12 hour online gaming stream, again with which the funds where donated to the Foundation.** **We are also partnered with AmazonSmile and EasyFundraising.**
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.**
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

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

Exemptions from disclosure

Reason for non-disclosure of key personnel details

Other optional information

Declarations

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

Signed on behalf of the charity's trustees

Signature(s)		H.V. Robinson
Full name(s)	Lee Reavey	Helen Robinson
Position (eg Secretary, Chair, etc)	Trustee	Chair
Date	01-04-2021	

CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name	No (if any)	
NIcolaides Baraitser Syndrome (NCBRS) Worldwide Foundation	1190194	**CC16a**

Receipts and payments accounts

For the period from	Period start date	To	Period end date
	30-06-2020		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	-	
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

	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	**01-04-2021**
	H.V.Robinson	**Helen Robinson**	**01-04-2021**