

RETT UK

England & Wales · Charity number 1137820

Details

Status	Registered
Legal form	Charitable company
Company number	07339522
Registered	2010-09-06
Register	View on the Charity Commission register

Contact

Address Victory House
Chobham Street
Luton
LU1 3BS

Phone 01582798910

Email info@rettuk.org

Website www.rettuk.org

Activities

Objects: TO PROMOTE THE CARE, WELFARE, TREATMENT AND ADVANCEMENT OF PEOPLE WITH RETT SYNDROME.TO SUPPORT, SUSTAIN AND ASSIST THOSE CARING FOR PEOPLE WITH RETT SYNDROME.TO PROMOTE GREATER UNDERSTANDING OF RETT SYNDROME.TO PROMOTE RESEARCH INTO THE CAUSES, EFFECTS AND METHODS OF PREVENTING RETT SYNDROME, AND TO DISSEMINATE OR PUBLISH THE RESULTS OF SUCH RESEARCH.

Activities: Rett syndrome is the most common cause of profound and multiple disability in females. A complex neurological condition genetic but not usually hereditary, it can occur in any family. We offer support, advocacy and advice to all those affected. We fund research to improve diagnosis, ameliorate symptoms and improve the quality of life of the thousands of people living with Rett syndrome today.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- **Area of benefit:** UNDEFINED.
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£341,168	£416,710	-	-
2024-03-31	£305,881	£318,560	-	-
2023-03-31	£365,072	£353,849	-	-
2022-03-31	£319,758	£311,442	-	-
2021-03-31	£347,557	£278,466	-	-

Trustees

Name	Role	Appointed
Clive Richard Beadle		2016-09-10
David Alfred Rogerson		2016-09-10
Debbie Cavaldoro		2025-09-11
Dee Cowburn		2025-09-11
Elliott James Le-Warde		2021-04-30
Joanna Campobello		2017-12-02
MICHAEL FREDERICK BRITTEN		
Mary Forest		2025-09-11
PHILIP RONALD GANDER		2016-09-10
Pauline Sophia Bardon		2019-12-07
Romi Loffler		2024-09-25
Stuart Neil Ledger		2019-01-23
Thomas Gander		2025-09-11

RETT UK

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Accounts

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

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FOR THE YEAR ENDED 31 MARCH 2025

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RETT UK
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CHAIR'S REPORT 2024-25
FOR THE YEAR ENDED 31 MARCH 2025

I would like to start with thanking the whole Rett UK team - Rob, Julie, Donna, Becky, Cherie, Abigail, Tracey, Becca and all those involved with Communications and Education Support - who continue to do an amazing job supporting the Rett Community. And I would like to acknowledge all our loyal fundraisers and sponsors who have made possible the continuing essential work of the charity. You can read more about the work during 2024-25 in the pages below.

Undoubtedly the highlight of the year was the Rett UK Family Weekend in Northampton in October 2024. This was the biggest in-person event that we have organised and it came with plenty of logistical challenges, before during and after the weekend itself. However, it was so good for the Rett family to be able to gather together in one place, with an amazing array of speakers, demonstrations and fun activities. On behalf of the whole Board of Trustees, I would like to thank Rob and the whole team who pulled out all the stops to prepare a bigger, better and entirely free weekend (thanks to a very successful Big Give campaign).

One of the strengths of the organisation is its committed and talented Board of Trustees. There has been great stability on the Board this year as all the Trustees have continued in post with just the one new Trustee (Tom Gander) joining the Board during the year. Continuity and togetherness has been required at times during the year as we have handled a number of difficult and sensitive issues, and it will be even more important in the year ahead as we enter choppier financial waters. As detailed elsewhere in this report Rett UK operated at a significant loss during 2024-25 and, while this was planned for and enabled us to make significant new investment in areas such as replacement eyegaze devices, it means that some additional funding and/or cost savings will be required in the coming year.

We live in challenging times economically and politically, but I am confident that we have a Board fully equipped and with the necessary experience to steer us through. Here's to another successful year in 2025/26.

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2025

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2025. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

About Rett Syndrome

Rett syndrome is a progressive, neurodevelopmental disorder. Rett syndrome is caused by mutations in the MeCP2 gene that lead to a deficiency of the methyl cytosine binding protein 2 (MeCP2), an important protein responsible for normal function in the brain and other parts of the nervous system. MeCP2 mutations much more commonly affect females, as the gene is found on the X-chromosome (which females have 2 copies of, whilst males only have 1).

Rett syndrome has an estimated worldwide incidence of 1 out of every 10,000-15,000 live female births, making it one of the most common genetic causes of developmental and intellectual impairment in females. The incidence in males is currently unknown.

People with Rett syndrome typically have normal development up until 6-18 months of age, but then experience rapid regression of previously acquired milestones including speech, gross and fine motor skills, and develop stereotypical, repetitive hand movements that prevent them from purposeful hand function. Over time people with Rett syndrome may develop muscle contractures, rigidity, and debilitating scoliosis, along with periods of recurrent seizures, burdensome gastrointestinal abnormalities, breathing abnormalities and cognitive decline.

Although there are treatments available for Rett syndrome, a significant unmet need still exists for new treatment options.

Objectives and aims

Our purpose

Rett UK is a national charity dedicated to supporting and empowering people with Rett syndrome, their families and those involved in providing their care. We are a membership organisation and welcome members from the UK and abroad.

Our strategic aims are to

- provide professional family-support services, activities and events at a local, regional and national level
- educate health, social care and education professionals about Rett syndrome to enable quicker diagnosis and improved standards of care throughout the UK
- advocate for people with Rett syndrome to be given the support and resources needed to be active communicators
- promote, support and encourage research into new therapies and treatments for Rett syndrome

Our vision

That everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

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REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31 MARCH 2025

OBJECTIVES AND ACTIVITIES

Public benefit

In shaping our objectives and planning our activities for the year, the Trustees have given consideration to the duties set out in section 17(5) of the Charities Act 2011 to have due regard to public benefit and to the Charity Commission Guidance on public benefit. In particular, the Trustees have considered how the planned activities will contribute to the overall aims and objectives that they have set.

The Trustees believe that the paragraph, specifically on "Achievements and Performance" for the year, relate in detail the benefit that the charity provides to the public.

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REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 MARCH 2025**

ACHIEVEMENTS AND PERFORMANCE

Charitable activities

Despite ending the year in a deficit 2024/2025 is up there with one of the most memorable years of late - primarily because we saw the return of the much loved and hugely valuable Family Weekend! The deficit was planned as we were using designated funds to bring the Family Weekend to our families free of charge, ensuring no one missed out on such an important event in terms of support, learning more about Rett syndrome and a chance to just be with other families walking the same path.

Throughout the year though the support for our families is unwavering including outside of office hours. One of the strengths of Rett UK is undoubtedly the commitment and dedication of our staff team who are always there to respond to parents messages and calls with knowledge and empathy.

We end the year with a deficit of £75,542 and a cash balance of £123,427 at 31 March 2025.

Connecting Families and Reducing Isolation

Our Family Support team remains the primary point of contact for individuals affected by Rett syndrome. This year demand has grown hugely, mainly driven by the desperate shape of local services the families rely on - health, education and social services. Lack of respite, Education Health and Care Plans that are not fit for purpose, key therapies such as speech and language therapy hugely oversubscribed and lengthy waiting list for life saving surgery putting enormous strain on families that are already living on a knife edge.

We are now providing support to over 1250 individuals with Rett syndrome and their families, over 900 interactions each quarter via our helpline, email, direct correspondence, responses on Facebook, WhatsApp, Twitter, Instagram, and Facebook Messenger.

These contact points serve a wide range of purposes - from individuals looking for information about Rett syndrome or specific symptoms, to emotionally intense calls from families facing a recent diagnosis. Because the nature and length of these calls can vary greatly, our dedicated family support team is highly trained and skilled in handling each one with care. They offer empathy, reassurance, guidance, practical advice, and relevant information, always mindful of the unique needs of every person who reaches out.

Family Support

The lengthy wait for surgery this year has been a significant challenge and stress point for many of our families. Scoliosis surgery (correcting a curvature in the spine) and fitting a gastrostomy (supplementary feeding tube inserted in the stomach) are two of the common surgeries individuals with Rett syndrome face. Not only have families been waiting months and months to get an actual date but also finding this then can get cancelled several times. The emotional strain this puts on families cannot be underestimated. We are here to support them but also advocate on their behalf pressing how critical the surgery is especially for scoliosis as the curve can reach a point where it is actually too dangerous to operate.

Rett UK & Rare Minds Counselling Service

We recognise how challenging parenting a child/adult with Rett syndrome can be and that sometimes things can become overwhelming for parents/carers. We know there are gaps in services and long waiting lists for counselling through the GP service. We also wanted counsellors who understand the pressures and strains caring for someone with a Rare Disease. We were delighted to partner with Rare Minds, to be able to offer a specific services to our families. The pilot scheme is currently running for 12 months, thanks to those generous people who supported and donated to our Big Give Christmas Challenge 2024

Rett Gents

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REPORT OF THE TRUSTEES **FOR THE YEAR ENDED 31 MARCH 2025**

We acknowledge the importance of Male Mental Health, by offering the opportunity for all males relatives, whatever their role is in supporting someone with Rett syndrome, to come together, to share experiences, talk to other dads and also to share information to others along this journey. Two dads, Brett Martin & Steve Nangreave, host the online meetings every six weeks, and they are looking at how they can create some face to face get togethers too.

Rett Insights

In April we launched the Rett Insights via our social media platforms, weekly snapshots of information about common issues for people with Rett syndrome, linked to more in-depth information via our website.

Rett UK Family Weekend 2024

We were delighted to be able to hold our Family Weekend in Coventry in October 2024. This much anticipated event had a record attendance with over 100 families including 84 people with Rett syndrome, the biggest ever gathering of people with Rett syndrome to date.

There was an excellent programme featuring some key speakers on medical topics such as Epilepsy/Movement Disorders, GI symptoms in Rett, Respiratory Issues & Preventative Treatments, Breathing, Scoliosis & Spinal Surgery, as well as Court of Protection, Wills & Trusts, Communication with presentations from people with Rett syndrome; another first!

Saturday evening, saw the amazing Gala Dinner, an opportunity for families to come together. The feedback from the event was extremely positive:

"It was AMAZING, it is many years since we attended a family weekend. I was so very impressed about how much the whole ethos. Not only was it informative it was so lovely to be there amongst people who truly understand."

"This was a great event for us as parents but my favourite bit is our other daughter coming home with contact details for a new group of friends who understand living with a sibling that has Rett. That has been worth more than anything seeing her confidence grow with peers. Thank you."

University of Reading Research Collaboration

Our collaboration with the University of Reading continues to go from strength to strength, with four Speech and Language Therapy research projects underway this academic year involving seven final-year students. These projects build on previous work and focus on:

- understanding communication between children with Rett syndrome and their partners;
- adapting language assessments for adolescents with complex needs;
- updating and evaluating the impact of the Rett Syndrome Communication Guidelines through surveys of parents, carers, and professionals.

The aim is to provide feedback to Rett UK and Regional Communication Champions, and to publish findings in peer-reviewed journals, helping to shape best practice nationally and internationally.

Alongside this, we launched a Speech and Language Therapy Peer Support Group in 2024, which now connects 12 active SLTs through regular online meetings, sharing expertise on assessment and target setting. We have also continued to deliver Communication Partner Training, drop-in clinics, and online peer groups.

Communication Professionals Network

The Communication Professionals Network, established with the backing of Rett UK's proficient Communication and Education team, continues to thrive. This dynamic network caters to professionals engaged with individuals having Rett syndrome, regardless of their setting, age group, level of expertise, or geographical location within the UK.

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FOR THE YEAR ENDED 31 MARCH 2025

Membership to this invaluable network involves a one-time enrollment fee, granting access to a wealth of exceptional resources and team-backed support, complemented by the provision of comprehensive communication guidelines. Alongside these benefits, each member receives a copy of the communication guidelines as a valuable reference. Explore the network's offerings and connect with like-minded professionals at www.rettuk.org/CPN.

9th World Congress in Rett Syndrome - Brisbane, Australia - October 2024

This was a stellar event organised by the Rett Syndrome Association of Australia over 4 days. We two streams of presentations running - a family stream and a scientific/clinical one - the audience could here the latest news and advances in understanding on all aspects of Rett syndrome from daily living through to gene therapies.

Rett UK was very well represented by our CEO Robert Adamek, along with Gill Townend and Becky Jenner, who was also representing (and funded by) Rett Syndrome Europe. This enabled us to see more talks and share notes, key points and learning which we could bring back to our support team and families.

There were fantastic networking opportunities as well - every parent organisation with a representative present took to the platform to share news and information about their countries work, allowing for collaboration and a greater understanding of each other's challenges.

The gala dinner at Sea World was a real highlight with so many Rett families attending alongside clinicians, researchers, scientists and therapists - what was so evident was the shared passion for a better life for people with Rett syndrome - a real hope for the future and a determination to see transformative treatments.

Loan Device Programme

Over the past year, our Loan Device Programme has continued to deliver a professionally structured service that offers tailored online support. The programme begins with an initial 8-week loan period, extendable up to 6 months, and includes dedicated guidance from a Communication and Education Support Champions.

We've enhanced our loan guide pack to better align with NHS funding application requirements, ensuring families are well-prepared to demonstrate progress in using Augmentative and Alternative Communication (AAC) systems.

Family Feedback:

"Taking part in the eye gaze trial has opened up a whole new world for us. For the first time, we've been able to see how much our daughter can express and understand. The support from the Rett UK team has been incredible, and we're overjoyed that this trial has led to securing the equipment she now depends on every day."

EHCP Support

This year again has seen a marked rise in requests for support with Education, Health and Care Plans (EHCPs). Our experienced team has assisted many families through both new applications and ongoing EHCP reviews.

Last year we expanded our service to include advocacy at Annual Reviews and, where possible, offer support to education professionals in both specialist and mainstream settings-especially around communication and Rett syndrome-specific needs. This has been invaluable to families.

The growing demand reflects how crucial this support is. Many families continue to seek clarity around what EHCPs involve, their entitlements, and the timelines they must navigate. We've recognised a clear need for more in-depth, accessible guidance, as families often feel uncertain about how to influence the content and quality of these documents.

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Communication Champions

Our CC team continues to meet monthly, with additional training sessions and collaborative meetings held as needed. These extra sessions are designed to build confidence in resource creation and to support our newly appointed CC.

We're pleased to see how smoothly new CC have integrated into the team, bringing energy and fresh perspectives. The mentoring relationships between experienced and new CC have been especially valuable, enabling skill-sharing and practical involvement-particularly through hands-on experience with the Loan Device Programme.

Looking ahead, we remain focused on growing our CC network into currently uncovered regions, allowing us to expand our reach and offer communication support to more families affected by Rett syndrome. We were also able to facilitate out and about groups in 7 areas with a total of 57 families signing up. These are in a local place of interest such as a wildlife park or museum providing rich opportunities to practise communication strategies with the support of the CC and other families.

New Courses

Our experienced team developed 2 new ones during the year: SETT Framework and Modelling. The courses are based on the SETT Framework by Joy Zabala and takes into account the Student, the Environment, the Tasks and the Tools. It is more for professionals or those a bit further along with their communication.

Social Media

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FOR THE YEAR ENDED 31 MARCH 2025

This year we've seen just how powerful our social media can be in bringing families together and sharing real stories. Facebook continues to be where we reach the most people, especially when we ask families to get involved, whether it's sharing World Book Day costumes, photos from Family Weekend, or words of support on Mother's Day. Posts that show people and personal experiences always spark the biggest reactions, far more than graphics or event adverts. Some of our biggest highlights included the Big Give campaign, Family Weekend, the Sibling Awards, and our Literacy campaign, all of which received wonderful engagement from our community. Updates on research, such as the latest from Taysha, also reached and resonated strongly, showing how important it is to balance family voices with hope for the future.

Partnerships, Alliances, Campaigning and Awareness Raising

As we continue our partnership with Reverse Rett under the RDA banner, we recognise the critical importance of collaboration in a rapidly evolving landscape of medical and technological advancements. By working together, we strengthen our shared expertise and ensure we are ready to respond as new treatments and innovations become available. This united approach keeps us at the forefront of progress, ensuring that the entire UK Rett community can access and benefit from the latest breakthroughs.

Disabled Children's Partnership

As members of the Partnership, we have worked closely with other organisations to campaign on a wide range of issues affecting disabled children, young people, and their families. Together, we have been able to raise awareness, share expertise, and strengthen our collective voice to ensure that the needs and rights of disabled people are not overlooked.

We are also now active members of the newly re-formed Public Affairs Group Meeting, which brings organisations together to coordinate efforts in influencing decision-makers. The group is particularly focused on building constructive relationships with politicians and policymakers to push for meaningful change.

Rett UK is also a member of The Helplines Partnership, Genetic Alliance UK, Embracing Complexity, The NVCO, Bedfordshire Chamber of Commerce.

NHS Clinics

Our specialist Rett clinics are now fully operational across four locations: Cardiff, Manchester, London, and Nottingham. Manchester and Nottingham have resumed in-person appointments, while the London clinic continues to operate virtually, an approach that has proven highly effective for families located across the UK.

Virtual clinics reduce the strain of travel and allow clinicians to observe children in their home environments, often providing deeper insights into their daily needs. When an in-person assessment is required, the clinic team will arrange face-to-face appointments to ensure families receive the most appropriate support.

These clinics are a lifeline for families who struggle to access local professionals with expertise in Rett syndrome. We remain committed to strengthening and expanding the capabilities of this vital service.

Rett UK is deeply committed to supporting families living with the daily challenges of Rett syndrome. Our work goes beyond clinical care, we focus on reducing isolation, building emotional resilience, and empowering families to become strong advocates for their children.

We help improve overall well-being, nurture healthy family relationships, and ensure families access the financial support and benefits they are entitled to. Through these efforts, Rett UK continues to make a meaningful, lasting impact, helping to shape a brighter and more secure future for everyone affected by this complex and devastating condition.

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REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31 MARCH 2025

FINANCIAL REVIEW

Principal funding sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Investment policy and objectives

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary / advisor who is authorised by the FCA. Recommendations will be brought to the Board of Trustees at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to The Board of Trustees, normally by e-mail, for comment/agreement within 7 days.

Rett UK's investments currently comprise cash held on deposit with Hampshire Trust Bank. This enables easy and speedy access to funds and reflects the Board's low risk approach to investments.

Reserves policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months' running costs, calculated against the current year's budgeted general expenditure. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations. In addition reserves are held where funds are raised for dedicated projects. At 31 March 2024 reserves are higher than our policy as funds from additional fundraising are being held to pay for national Family Weekend in 2024. This is a substantial event and to support the event it is anticipated that further funding will be raised in the year to support this key event.

Rett UK will regularly monitor its reserves via the Honorary Treasurer and CEO who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a company limited by guarantee, incorporated on 9 August 2010 and registered as a charity on 6 September 2010.

The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed by its Articles of Association. Copies of the Articles of Association are available at www.rettuk.org or from its Head Office by request.

The charity was formed to continue the work of Rett Syndrome Association UK (working name RSAUK) a charity registered in 1986, and given a more succinct name.

The members have guaranteed to contribute a maximum of £10 each in the event of the company being wound up.

RETT UK

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2025

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

The charity is governed and overseen by its Trustee Board which comprises of twelve individuals with a mix of experience of Rett Syndrome. The Board operated two Sub Committees, a Management Sub Committee that oversees the running and administration of the charity and a Finance Sub Committee that oversees all financial matter for the charity. The day to day running of the charity is delegated to the Chief Executive Officer, Robert Adamek.

Appointment, and Induction and training of new trustees

The Directors are Charity Trustees as defined by section 177 of the Charities Act 2011. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

Internal Control and Risk management

The Board of Trustees is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the CEO who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a three-year Business Plan written by the CEO and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules which the Charity faces, the Board of Trustees confirms that systems have been established to minimise organisational and financial risks.

The Board of Trustees has established two sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees.

The Finance Committee, Chaired by the Treasurer, discusses and agrees the annual budget (including approving salary reviews) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary / adviser who is authorised by the FCA. It reviews the annual audit plan of the external organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

The Management Committee reviews and discusses personnel and general management issues before making recommendations to the Board of Trustees. It also has responsibility for reviewing the policies and procedures of Rett UK; the majority are reviewed every three years with the exception of The Safeguarding Children and Vulnerable Adults Policy, The Finance Policy and The Reserves Policy which are reviewed annually. Other policies may be reviewed when a change in legislation or guidance necessitates it.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
7339522 (England and Wales)

Registered Charity number
1137820

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REPORT OF THE TRUSTEES

FOR THE YEAR ENDED 31 MARCH 2025

Registered office

Victory House
Chobham Street
Luton
Bedfordshire
LU1 3BS

Trustees

Mr M Britten
Mr P R Gander
Mr D A Rogerson
Mr C R Beadle
Mrs J Campobello
Mr S Ledger
Mrs P S Bardon
E J Le-Warde
Mrs D Cavaldoro (appointed 11/9/2025)
Mrs D Cowburn (appointed 11/9/2025)
Mrs M Forest (appointed 11/9/2025)
Mr T Gander (appointed 11/9/2025)
Miss R Loffler (appointed 11/9/2025)

Independent Examiner

Dr Shona F Wardrop C.A.
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31 MARCH 2025

REFERENCE AND ADMINISTRATIVE DETAILS

Bankers

Metro Bank plc
One Southampton Row
London
WC1B 5HA

HSBC
Ballards Lane
Church End
Finchley
London
N3 2BH

Hampshire Trust Bank plc
PO Box 74003
London
EC2P 2QR

Cambridge & Counties Bank
Charnwood Court
5b New Walk
Leicester England
LE1 6TE

Honorary President

Yvonne Milne MBE

Honorary Vice President

Lorna Jaffa as Vice

Approved by order of the board of trustees on6th December 2025..... and signed on its behalf by:



.....
Mr D A Rogerson - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
RETT UK
(A COMPANY LIMITED BY GUARANTEE)**

Independent examiner's report to the trustees of Rett UK (A company limited by guarantee) ('the Company')
I report to the charity trustees on my examination of the accounts of the Company for the year ended 31 March 2025.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants of Scotland, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Shona Wardrop

Dr Shona F Wardrop C.A
The Institute of Chartered Accountants of Scotland

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Date: 22 December 2025

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31 MARCH 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	285,501	45,000	330,501	299,772
Other trading activities	3	8,052	-	8,052	5,873
Investment income	4	2,615	-	2,615	236
Total		<u>296,168</u>	<u>45,000</u>	<u>341,168</u>	<u>305,881</u>
EXPENDITURE ON					
Raising funds		103,309	-	103,309	73,501
Charitable activities					
Charitable activities		313,401	-	313,401	245,059
Total		<u>416,710</u>	<u>-</u>	<u>416,710</u>	<u>318,560</u>
NET INCOME/(EXPENDITURE)		(120,542)	45,000	(75,542)	(12,679)
RECONCILIATION OF FUNDS					
Total funds brought forward		188,125	7,742	195,867	208,546
TOTAL FUNDS CARRIED FORWARD		<u>67,583</u>	<u>52,742</u>	<u>120,325</u>	<u>195,867</u>

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET
31 MARCH 2025

	Notes	Unrestricted funds £	Restricted funds £	2025 Total funds £	2024 Total funds £
CURRENT ASSETS					
Debtors	10	14,980	-	14,980	16,614
Cash at bank		55,705	52,742	108,447	217,533
		<u>70,685</u>	<u>52,742</u>	<u>123,427</u>	<u>234,147</u>
CREDITORS					
Amounts falling due within one year	11	(3,102)	-	(3,102)	(38,280)
		<u>67,583</u>	<u>52,742</u>	<u>120,325</u>	<u>195,867</u>
NET CURRENT ASSETS					
		<u>67,583</u>	<u>52,742</u>	<u>120,325</u>	<u>195,867</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>67,583</u>	<u>52,742</u>	<u>120,325</u>	<u>195,867</u>
NET ASSETS					
		<u>67,583</u>	<u>52,742</u>	<u>120,325</u>	<u>195,867</u>
FUNDS					
Unrestricted funds	13			67,583	188,125
Restricted funds				52,742	7,742
				<u>120,325</u>	<u>195,867</u>
TOTAL FUNDS					
				<u>120,325</u>	<u>195,867</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31 March 2025.

The members have not required the company to obtain an audit of its financial statements for the year ended 31 March 2025 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

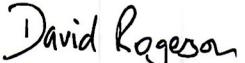
The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET - continued
31 MARCH 2025

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on6th December 2025..... and were signed on its behalf by:


.....
Mr D A Rogerson - Trustee

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2025

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future, and on that basis the charity is considered to be a going concern.

The financial statements are prepared in sterling which is the functional currency of the entity, and are rounded to the nearest £1.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Income from Grants is deferred where performance-related conditions outside of the control of the charity are attached.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery	- 25% and 50% on cost
Fixtures and fittings	- 25% and 50% on cost
Computer equipment	- 25% and 50% on cost

The charity does not capitalise fixed assets costing less than £500.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK Corporation Tax purposes. Accordingly the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

1. ACCOUNTING POLICIES - continued

Fund accounting

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals payable under operating leases are charged to the Statement of Financial Activities in the year in which they are payable.

Pensions

The pension cost charge represents the contribution payable by the Charity to the employers' defined contribution pension scheme.

Judgements and key sources of estimation uncertainty

In the application of the charity's accounting policies, the charity is required to make judgments, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both the current and future periods.

There are no estimates and assumptions that are considered to have a significant risk of causing a material adjustments to the financial statements in a future period.

Financial instruments

The charity has only financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their settlement value with the exception of bank loans which are measured at amortised cost using the effective interest method.

Financial Assets

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any discounts due.

Financial Liabilities

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any discounts due.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

2. DONATIONS AND LEGACIES

	2025	2024
	£	£
Donations	155,002	205,304
Legacies	23,418	-
Grants	152,081	94,468
	<u>330,501</u>	<u>299,772</u>

Grants received, included in the above, are as follows:

	2025	2024
	£	£
Bartle Family Charitable Trust	1,000	1,000
BBC Children in Need	-	43,345
St James' Place Foundation	-	2,500
David Solomon Charitable Trust	-	750
The Baily Thomas Charitable Fund	-	20,000
The Edgar Lee Foundation	2,200	1,350
The Souter Charitable Trust	3,000	-
The Woodroffe Benton Foundation	-	2,000
The Thomas Siveright Catto Charitable Settlement	750	-
Twyford And District Round Table	1,000	-
Tower Bridge	4,031	13,503
Priavo Security	-	1,020
Kaye Charitable Trust	-	1,000
MK Charitable trust	-	2,000
Michael Cornish Charitable Trust	-	1,000
The D'Oyly Carte Charitable Trust	-	4,000
ICECO Limited	-	1,000
Orr Mack Foundation	5,000	-
AXIS Specialty Europe Limited	1,000	-
Big Giving Campaign	123,100	-
Douglas Arter Foundation	1,000	-
The Stockwell Charitable Trust	5,000	-
Delamere Dairy Foundation	5,000	-
	<u>152,081</u>	<u>94,468</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

3. OTHER TRADING ACTIVITIES

	2025	2024
	£	£
Sales	-	173
Unity Lottery and 300 Club	3,684	4,436
Other receipts	4,368	1,264
	<u>8,052</u>	<u>5,873</u>

4. INVESTMENT INCOME

	2025	2024
	£	£
Deposit account interest	<u>2,615</u>	<u>236</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2025	2024
	£	£
Independent Examiner	<u>2,555</u>	<u>2,405</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2025 nor for the year ended 31 March 2024.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31 March 2025 nor for the year ended 31 March 2024.

7. STAFF COSTS

	2025	2024
	£	£
Wages and Salaries	185,419	175,919
Social Security	13,134	12,417
Employers' Pension	<u>3,042</u>	<u>2,827</u>
	201,595	191,163
Other Staff Costs	<u>43,076</u>	<u>48,164</u>
	<u>244,671</u>	<u>239,327</u>

The average monthly number of employed personnel during the year was:

2025	2024
------	------

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

7. STAFF COSTS - continued

Average number	<u>6</u>	<u>6</u>
On a full time equivalent basis	<u>5</u>	<u>5</u>

There are also self employed personnel equating to a further 1 (2024: 1) member on a full time equivalent basis.

Key Management personnel (being the Trustees and the Chief Executive Officer) remuneration (comprising gross salary, employers' national insurance and employers' pension) amounted to £58,870 (2024: £56,148)

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	299,772	-	299,772
Other trading activities	5,873	-	5,873
Investment income	236	-	236
Total	<u>305,881</u>	<u>-</u>	<u>305,881</u>
EXPENDITURE ON			
Raising funds	73,501	-	73,501
Charitable activities			
Charitable activities	245,059	-	245,059
Total	<u>318,560</u>	<u>-</u>	<u>318,560</u>
NET INCOME/(EXPENDITURE)	(12,679)	-	(12,679)
RECONCILIATION OF FUNDS			
Total funds brought forward	200,804	7,742	208,546
TOTAL FUNDS CARRIED FORWARD	<u>188,125</u>	<u>7,742</u>	<u>195,867</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

9. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1 April 2024 and 31 March 2025	250	2,472	2,183	4,905
DEPRECIATION				
At 1 April 2024 and 31 March 2025	250	2,472	2,183	4,905
NET BOOK VALUE				
At 31 March 2025	-	-	-	-
At 31 March 2024	-	-	-	-

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Trade debtors	-	150
Prepayments	14,980	16,464
	<u>14,980</u>	<u>16,614</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2025 £	2024 £
Other creditors	702	-
Accruals and deferred income	2,400	38,280
	<u>3,102</u>	<u>38,280</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

12. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2025 £	2024 £
Within one year	-	912

13. MOVEMENT IN FUNDS

	At 1/4/24 £	Net movement in funds £	At 31/3/25 £
Unrestricted funds			
General fund	188,125	(120,542)	67,583
Restricted funds			
Research Fund	7,742	-	7,742
Big Give	-	31,000	31,000
Eyegaze Fund	-	14,000	14,000
	<u>7,742</u>	<u>45,000</u>	<u>52,742</u>
TOTAL FUNDS	<u>195,867</u>	<u>(75,542)</u>	<u>120,325</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	296,168	(416,710)	(120,542)
Restricted funds			
Big Give	31,000	-	31,000
Eyegaze Fund	14,000	-	14,000
	<u>45,000</u>	<u>-</u>	<u>45,000</u>
TOTAL FUNDS	<u>341,168</u>	<u>(416,710)</u>	<u>(75,542)</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

13. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/23 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	200,804	(12,679)	188,125
Restricted funds			
Research Fund	7,742	-	7,742
TOTAL FUNDS	<u>208,546</u>	<u>(12,679)</u>	<u>195,867</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	305,881	(318,560)	(12,679)
TOTAL FUNDS	<u>305,881</u>	<u>(318,560)</u>	<u>(12,679)</u>

Research Funds

All monies in the Research Funds are utilised to support possible treatments and cures.

14. EMPLOYEE BENEFIT OBLIGATIONS

The charitable company operates a defined contribution pension scheme with contributions being made by both employer and employees at variable rates. Total pension costs in the current year amounted to £3,042 (2024: £2,827). At the year end £702 was due to the provider (2024: £nil).

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31 MARCH 2025

15. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31st March 2025.

E J Le-Warde, a Trustee, is the son of a member of staff.

RETT UK

England & Wales - Charity number 1137820

Accounts

REGISTERED COMPANY NUMBER: 7339522 (England and Wales)
REGISTERED CHARITY NUMBER: England and Wales 1137820, Scotland SC047369

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST MARCH 2024
FOR
RETT UK
(A COMPANY LIMITED BY GUARANTEE)

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

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FOR THE YEAR ENDED 31ST MARCH 2024

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RETT UK
(A COMPANY LIMITED BY GUARANTEE)

CHAIR'S REPORT 2023-24
FOR THE YEAR ENDED 31ST MARCH 2024

I would like to start with thanking the Rett UK team who continue to an amazing job, the Rett Community and all those that have supported the charity over the last year.

I am writing this as the final preparations are being made for the Rett UK Family Weekend being held in Northampton in October 2024. It has been a long time since we organised a in person event of this scale, but with the Covid-19 pandemic now firmly behind us, the time felt right for a big event. Rob and the whole team have pulled out all the stops to prepare a bigger, better and entirely free weekend (thanks to our sponsors and a very successful Big Give campaign). I know that the programme will showcase and celebrate all aspects of the charity's work from family support to communication workshops and the latest updates on gene therapies and treatments. But even more important, it will be a chance for the Rett Community to come together in person to learn from and support one another. If, like me, you are unable to attend, then look out for the reports on our website and in Rett News.

Just as the staff team have had a busy year, so also it has been an eventful twelve months on the Board. Much effort went into preparing a new Strategic Plan, we have made good progress reviewing and updating our policies and procedures and we have managed to maintain a healthy financial position in a challenging economic environment. In fact, we have been so successful at fund-raising that we are carrying more reserves than we ideally should. This has enabled us to invest in support functions such as IT and the website, but in the year ahead we are planning more significant investments in frontline activities such as expanding our family support team under Julie's leadership and purchasing new eye-gaze devices to replace our ageing devices which are loaned to Rett families as part of the critical communication support we provide. I am very grateful for all the fundraising activities that have been going on this year giving us the financial base to enable this to happen (and to Donna for her unstinting efforts to provide administrative support to all our intrepid fundraisers).

The Board of Trustees comprises 12 talented and committed individuals and I would like to thank each one of them for their contributions this year. We have a great balance of skill sets, a mix of youth and experience, a good gender balance and a healthy mix of people with and without direct family experience of Rett syndrome. It has been thrilling this year to have Romi Löffler join us - the first person with Rett syndrome to join the Board. The Board has had to learn new ways of working so that Romi can fully and equally participate at Board meetings, which has ultimately improved the way it works. Romi's insight into what it means to live with Rett is really valuable. It is a tremendous testament to Romi, her parents and her communication partners, that this has been at all possible. Hers is a marvellous example of people with Rett syndrome fulfilling their potential. As a charity we aim to help support every person with Rett syndrome to discover and fulfil their own potential, recognising that this is different for each person.

Onwards and upwards into another year!

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st March 2024. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

About Rett Syndrome

Rett syndrome is a progressive, neurodevelopmental disorder. Rett syndrome is caused by mutations in the MeCP2 gene that lead to a deficiency of the methyl cytosine binding protein 2 (MeCP2), an important protein responsible for normal function in the brain and other parts of the nervous system. MeCP2 mutations much more commonly affect females, as the gene is found on the X-chromosome (which females have 2 copies of, whilst males only have 1).

Rett syndrome has an estimated worldwide incidence of 1 out of every 10,000-15,000 live female births, making it one of the most common genetic causes of developmental and intellectual impairment in females. The incidence in males is currently unknown.

People with Rett syndrome typically have normal development up until 6-18 months of age, but then experience rapid regression of previously acquired milestones including speech, gross and fine motor skills, and develop stereotypical, repetitive hand movements that prevent them from purposeful hand function. Over time people with Rett syndrome may develop muscle contractures, rigidity, and debilitating scoliosis, along with periods of recurrent seizures, burdensome gastrointestinal abnormalities and breathing abnormalities.

Objectives and aims

Our purpose...

Rett UK is a national charity dedicated to supporting and empowering people with Rett syndrome, their families and those involved in providing their care. We are a membership organisation and welcome members from the UK and abroad.

Our strategic aims are to ...

- provide professional family-support services, activities and events at a local, regional and national level
- educate health, social care and education professionals about Rett syndrome to enable quicker diagnosis and improved standards of care throughout the UK
- advocate for people with Rett syndrome to be given the support and resources needed to be active communicators
- promote, support and encourage research into new therapies and treatments for Rett syndrome Our vision...

That everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

OBJECTIVES AND ACTIVITIES

Public benefit

In shaping our objectives and planning our activities for the year, the Trustees have given consideration to the duties set out in section 17(5) of the Charities Act 2011 to have due regard to public benefit and to the Charity Commission Guidance on public benefit. In particular, the Trustees have considered how the planned activities will contribute to the overall aims and objectives that they have set.

The Trustees believe that the paragraph, specifically on "Achievements and Performance" for the year, relate in detail the benefit that the charity provides to the public.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

ACHIEVEMENT AND PERFORMANCE

Charitable activities

This has been a very positive year where we have remained committed to consistently providing great quality support to our families and the Rett community. Over the past year we have rolled out numerous successful projects, including our online conference which saw record attendance.

Our engagement has extended to attending a multitude of meetings, where we've been able to stand beside families during their most difficult moments, offering steadfast advocacy support. We also continued to connect families with a network of Rett professionals, fostering connections that might otherwise never have been made.

We end the year with a deficit of £12,679 and a cash balance of £217,533 at 31 March 2024.

Connecting Families and Reducing Isolation

Our Family Support service remains the primary point of contact for individuals affected by Rett syndrome. The demand for assistance continues to surge, with an increasing number of families initially reaching out through social media platforms and subsequently becoming members, thereby gaining access to the full spectrum of support services we offer.

Each quarter witnesses an overwhelming engagement, totalling more than 800+ interactions with family members. These interactions encompass calls to our helpline, communications via our support email, direct correspondence, responses on Facebook, WhatsApp, Twitter, Instagram, and Facebook Messenger.

These points of contact serve diverse purposes, ranging from seeking information about Rett syndrome or specific symptoms to emotionally charged calls from families grappling with a new diagnosis. As their intensity and duration vary, our dedicated family support team is equipped with extensive skills and training to address each call effectively. They provide comfort, empathy, guidance, advice, and pertinent information, understanding the unique needs of every individual who reaches out to us.

The demand for our services continues to grow, and we are committed to meeting it by continually bolstering our resources and expertise wherever necessary.

Family Support

A key challenge we faced this year has been the lengthy process involved in receiving genetic test results. While the increasing use of whole genome testing by paediatricians is a positive step forward, providing a more comprehensive identification of genetic defects, it has led to extended waiting times, often ranging from 12 to 18 months. This delay has understandably caused significant distress for many families. To help ease this burden, we have been advocating for clinicians to consider clinical diagnoses based on patient symptoms and established criteria, offering a possible solution while awaiting genetic confirmations.

Rett UK Online Conference 2023

The team delivered an outstanding event this year, with over 850 registrations and 798 attendees across nearly 50 sessions. We hosted 33 speakers, and all talks were meticulously hand-subtitled for accessibility. The event's success has been reflected in the excellent feedback and engagement we've received, as well as the ongoing re-engagement with our services. Our marketing team will continue to promote the recorded talks to ensure sustained engagement.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

Database

We successfully launched our database project in January, thanks to funding from CAF, and it has already started delivering tangible benefits. While there were a few initial challenges, our ongoing monthly collaboration with our database provider, has helped resolve legacy data issues and ensure that all reporting features are fully aligned with our needs. In addition, we are running complementary projects to further enhance the system's efficiency and functionality. One exciting development is the integration of an Outlook plugin, allowing seamless communication to be directly added to the database. This has significantly improved our service quality and streamlined operations, enabling us to offer even better support.

Research Partnership with Reading University & Gill Townend

We have now embarked on a three-year project in partnership with Reading University. Gill will be working with a group of speech and language therapy students from the university for one day every week. Together, they will conduct targeted research to improve the effectiveness of our communications efforts. Initially, our focus will be on the Communications Professionals Network, and we aim to provide support to our Regional Communication Coordinators (RCCs).

Communication Professionals Network

The Communication Professionals Network, established with the backing of Rett UK's proficient Communication and Education team, continues to thrive. This dynamic network caters to professionals engaged with individuals having Rett syndrome, regardless of their setting, age group, level of expertise, or geographical location within the UK.

Membership to this invaluable network involves a one-time enrolment fee, granting access to a wealth of exceptional resources and team-backed support, complemented by the provision of comprehensive communication guidelines. Alongside these benefits, each member receives a copy of the communication guidelines as a valuable reference. Explore the network's offerings and connect with like-minded professionals at www.rettuk.org/CPN.

Trust and Foundations Trainee

We are delighted to share that we welcomed a new team member to Rett UK this year. Cherie Hunter has joined us as a Trainee Trust and Foundation Fundraiser. Cherie will be collaborating closely with Becky to gain a deep understanding of the role. Her passion for our mission is deeply personal, having experienced our support firsthand when we assisted her family and her late sister, Charlotte. We are confident that Cherie's personal connection to Rett UK will provide her with a unique perspective, enhancing her contribution to the team.

European Congress in Marseille

The Rett Syndrome Association of France hosted the 2023 European Congress in Marseille on the 7th and 8th of October. This marked the first major in-person event for many of us in the last five years, and both Abigail and I were honored to attend.

Day 1 of the 7th European Rett Syndrome Conference provided valuable updates on rare disease strategies, clinical trials, and the latest discoveries in Rett Syndrome research. Key topics included epilepsy management, breathing difficulties, and the daily challenges faced by those living with Rett syndrome. We also explored technological advancements in Augmentative and Alternative Communication (AAC) during the networking breaks.

On Day 2, the focus shifted to innovative therapies, including discussions on neural precursor cell therapy and the genetic determinants of MECP2 reactivation. We delved into physical therapy practices, communication guidelines, and cutting-edge technologies, which all presented promising tools for improving the quality of life for individuals with Rett Syndrome. The event was a rich source of knowledge and inspiration for all attendees.

RETT UK
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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

Rett Syndrome Europe Event

Satellite meeting 17th and 18th March, Angela Ruskin University

Rett UK was delighted to partner with Rett Syndrome Europe for the first ever RSE Network Support and Research meeting. The main meeting was held in Budapest, Hungary, satellite meetings were held simultaneously in the UK, Netherlands, Serbia, Georgia, Croatia and Turkey.

The UK satellite event allowed us a fantastic opportunity to generate fresh interest in Rett syndrome, both in terms of research and clinical focus. We were thrilled to have a diverse group of attendees join us in person and remotely, including students, researchers, and professionals from Kings College London and Cambridge University.

Together, we agreed on the following key priorities for the UK:

- Maintaining the delivery of exceptional support services
- Increasing awareness of Rett syndrome
- Preparing the UK for potential future treatments

Loan Device Programme

Our program has grown and evolved professionally over the past year, offering unique online support. The loan program provides an initial 8-week term, extendable up to 6 months, with dedicated assistance from a Regional Communications Coordinator. We've improved the loan guide pack to align with NHS funding application readiness, ensuring effective tracking of progress with Augmentative and Alternative Communication (AAC).

Family Feedback: *"I cannot thank you and the Rett UK team enough for your support in trialling the communication device. It has been life-changing for us, and I'm thrilled to share that we received confirmation today that the funding for the equipment has been approved!"*

EHCP support

Throughout the year, our committed team has seen a significant increase in demand for EHCP support. We've assisted a large number of families with both new and ongoing EHCPs, broadening our services to include acting as expert advocates during Annual Reviews. Additionally, where possible, we've extended our assistance to professionals in both specialist and mainstream schools, focusing on communication challenges and Rett syndrome.

This growing demand highlights the essential need for our services. Many families are seeking clarity on EHCPs, their purpose, entitlements, and the various timelines involved. We've recognized a clear need for thorough guidance, as families often feel unsure about their role in influencing the content of these documents.

Friendship groups

The adult (16+) friendship group is now an established part of our events calendar and continues to meet online on a monthly basis. We continue to innovate in the groups as we continue to explore how we can work directly with people with Rett syndrome, to develop advocacy skills, and listen to what they tell us, we see the members of this adult group as important contributors to helping us shape the services and support we offer.

Regional Communication Champions

We currently hold a monthly meeting for RCC discussions, supplemented by additional meetings when necessary. These additional meetings are primarily intended for providing training to create resources and to offer assistance to the newly appointed RCCs. We are thrilled by the seamless integration of the new members of the team and their remarkable level of engagement. The mentorship dynamic between the veterans and the new team members is proving to be effective, as the newcomers have actively participated in resource generation and have also gained hands-on experience through their involvement in the loan program.

Additionally, we continue actively seeking to expand our team of RCCs to areas that are currently not covered, in order to extend our reach and provide support to even more individuals affected by Rett syndrome.

Communication partner training

This year, we revamped the Communication Partner training course to make it more interactive and less content-heavy. The feedback has been overwhelmingly positive, with 100% of participants finding all components helpful or very helpful and expressing that they would recommend the course to others. We observed a noticeable increase in participant confidence between the two sessions, and three families reported significant improvements in their child's communication following the first session.

Partnerships, Alliances, Campaigning and Awareness Raising

As we maintain our partnership with Reverse Rett under the RDA banner, we acknowledge the vital importance of unity in the face of advancing medical and technological developments. Working together not only deepens our collective knowledge but also ensures that, as new treatments and technologies emerge, we are well-prepared to adapt effectively. This collaboration allows us to stay at the forefront of support, ensuring that the entire UK Rett community fully benefits from these groundbreaking treatments and innovations.

Carer Poverty Coalition

We joined 50 other members of the Carer Poverty Coalition in writing to the Chancellor ahead of the Autumn statement, urging him to provide unpaid carers and the people they look after with the financial support they urgently need. Across the UK, at least 5.7 million people care for a loved one who is older, disabled, or seriously ill. Yet despite the invaluable support they provide, thousands are facing huge financial hardship, with 75% of those receiving Carer's Allowance struggling to make ends meet.

Disabled Children's Partnership

As members of the partnership, we were involved in the following campaigns over the course of the year:

#SENDABetterMessage - This campaign focuses on ensuring that the government's SEND reform programme creates a fairer, more accessible system of support for disabled children, making services easier to navigate and obtain without unnecessary battles.

#GiveItBack - A long-standing campaign that addresses the significant underfunding of disabled children's health and care services, calling on the government to reinvest in vital services for these children and families.

#FailedAndForgotten - Following the pandemic, this campaign highlights the unprecedented delays in health and social care services for disabled children, calling for urgent improvements to address backlogs.

DCP Manifesto - Leading up to the expected general election, this manifesto calls for major political parties to prioritise disabled children, advocating for the appointment of a Minister for Disabled Children and stronger accountability across the education, health, and social care systems.

We are also now part of the newly re-formed Public Affairs Group Meeting which has a focus on trying to engage with politicians to get things achieved. This looks like it has got off to a good start with commitments from senior Labour party members willing to engage immediately.

Rett UK is also a member of The Helplines Partnership, Genetic Alliance UK, Embracing Complexity, The NVCO, Bedfordshire Chamber of Commerce.

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

NHS Clinics

Our specialised Rett clinics operate across four locations: Cardiff, Manchester, London, and Nottingham. All clinics have returned to their regular schedules, with Manchester and Nottingham offering in-person appointments. London, on the other hand, has opted to continue conducting clinics virtually, a choice that has proven effective for families scattered across the UK. This approach minimises travel-related disruptions for families and their children. The added advantage of observing the child in their familiar environment has yielded positive results. In situations where clinic team members deem an in-person meeting necessary, such appointments will be arranged, ensuring face-to-face assessments for families.

This service proves invaluable for families struggling to find local experts with knowledge of this rare disorder. We persist in exploring avenues to enhance the capabilities of these clinics.

Rett UK remains dedicated to making a meaningful impact on families grappling with the daily challenges posed by Rett syndrome. Our efforts encompass various dimensions, from alleviating the isolation these families often experience, to empowering them as effective advocates for their children. We focus on bolstering their emotional resilience, enhancing their overall well-being, fostering positive intra-family relationships, and ensuring they access the entitled benefits to optimize their family's financial stability. Through these initiatives, Rett UK is actively shaping a brighter future for those affected by this devastating disorder

RETT UK
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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

FINANCIAL REVIEW

Principal funding sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Investment policy and objectives

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary / advisor who is authorised by the FCA. Recommendations will be brought to the Board of Trustees at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to The Board of Trustees, normally by e-mail, for comment/agreement within 7 days.

Rett UK's investments currently comprise cash held on deposit with Hampshire Trust Bank. This enables easy and speedy access to funds and reflects the Board's low risk approach to investments.

Reserves policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months' running costs, calculated against the current year's budgeted general expenditure. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations. In addition reserves are held where funds are raised for dedicated projects. At 31 March 2024 reserves are higher than our policy as funds from additional fundraising are being held to pay for national Family Weekend in 2024. This is a substantial event and to support the event it is anticipated that further funding will be raised in the year to support this key event.

Rett UK will regularly monitor its reserves via the Honorary Treasurer and CEO who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a company limited by guarantee, incorporated on 9 August 2010 and registered as a charity on 6 September 2010.

The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed by its Articles of Association. Copies of the Articles of Association are available at www.rettuk.org or from its Head Office by request.

The charity was formed to continue the work of Rett Syndrome Association UK (working name RSAUK) a charity registered in 1986, and given a more succinct name.

The members have guaranteed to contribute a maximum of £10 each in the event of the company being wound up.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

STRUCTURE, GOVERNANCE AND MANAGEMENT

Organisational structure

The charity is governed and overseen by its Trustee Board which comprises of twelve individuals with a mix of experience of Rett Syndrome. The Board operated two Sub Committees, a Management Sub Committee that oversees the running and administration of the charity and a Finance Sub Committee that oversees all financial matter for the charity. The day to day running of the charity is delegated to the Chief Executive Officer, Robert Adamek.

Appointment, and Induction and training of new trustees

The Directors are Charity Trustees as defined by section 177 of the Charities Act 2011. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

Internal Control and Risk management

The Board of Trustees is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the CEO who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a three-year Business Plan written by the CEO and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules which the Charity faces, the Board of Trustees confirms that systems have been established to minimise organisational and financial risks.

The Board of Trustees has established two sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees.

The Finance Committee, Chaired by the Treasurer, discusses and agrees the annual budget (including approving salary reviews) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary / adviser who is authorised by the FCA. It reviews the annual audit plan of the external organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

The Management Committee reviews and discusses personnel and general management issues before making recommendations to the Board of Trustees. It also has responsibility for reviewing the policies and procedures of Rett UK; the majority are reviewed every three years with the exception of The Safeguarding Children and Vulnerable Adults Policy, The Finance Policy and The Reserves Policy which are reviewed annually. Other policies may be reviewed when a change in legislation or guidance necessitates it.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number
7339522 (England and Wales)

Registered Charity number
England and Wales: 1137820
Scotland: SC047369

Registered office
Victory House
Chobham Street
Luton
Bedfordshire
LU1 3BS

Trustees
Mr M Britten
Mr P R Gander
Mr D A Rogerson
Mr C R Beadle
Mrs J Campobello
Mr S Ledger
Mrs P S Bardon
Mr A Sadek (resigned 19/7/2023)
E J Le-Warde

Independent Examiner
Dr Shona F Wardrop C.A
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2024

REFERENCE AND ADMINISTRATIVE DETAILS

Bankers

Metro Bank plc
One Southampton Row
London
WC1B 5HA

HSBC
Ballards Lane
Church End
Finchley
London
N3 2BH

Hampshire Trust Bank plc
PO Box 74003
London
EC2P 2QR

Cambridge & Counties Bank
Charnwood Court
5b New Walk
Leicester England
LE1 6TE

Patrons

Yvonne Milne MBE
Evelyn Glennie DBE
Gloria Hunniford
Jon Snow
Victoria Murphy

President

Yvonne Milne MBE

Vice President

Lorna Jaffa

Approved by order of the board of trustees on 28th September 2024 and signed on its behalf by:



.....
Mr D A Rogerson - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
RETT UK
(A COMPANY LIMITED BY GUARANTEE)**

Independent examiner's report to the trustees of Rett UK (A company limited by guarantee) ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31st March 2024.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants of Scotland, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Dr Shona F Wardrop C.A
The Institute of Chartered Accountants of Scotland

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Date:

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31ST MARCH 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	299,772	-	299,772	357,690
Other trading activities	3	5,873	-	5,873	7,227
Investment income	4	236	-	236	155
Total		<u>305,881</u>	<u>-</u>	<u>305,881</u>	<u>365,072</u>
EXPENDITURE ON					
Raising funds		73,501	-	73,501	79,666
Charitable activities					
Charitable activities		<u>245,059</u>	<u>-</u>	<u>245,059</u>	<u>274,183</u>
Total		<u>318,560</u>	<u>-</u>	<u>318,560</u>	<u>353,849</u>
NET INCOME/(EXPENDITURE)		(12,679)	-	(12,679)	11,223
RECONCILIATION OF FUNDS					
Total funds brought forward		200,804	7,742	208,546	197,323
TOTAL FUNDS CARRIED FORWARD		<u>188,125</u>	<u>7,742</u>	<u>195,867</u>	<u>208,546</u>

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET
31ST MARCH 2024

	Notes	Unrestricted funds £	Restricted funds £	2024 Total funds £	2023 Total funds £
CURRENT ASSETS					
Debtors	10	16,614	-	16,614	19,322
Cash at bank		<u>209,791</u>	<u>7,742</u>	<u>217,533</u>	<u>234,759</u>
		226,405	7,742	234,147	254,081
CREDITORS					
Amounts falling due within one year	11	(38,280)	-	(38,280)	(45,535)
		<u>188,125</u>	<u>7,742</u>	<u>195,867</u>	<u>208,546</u>
NET CURRENT ASSETS					
		<u>188,125</u>	<u>7,742</u>	<u>195,867</u>	<u>208,546</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>188,125</u>	<u>7,742</u>	<u>195,867</u>	<u>208,546</u>
NET ASSETS					
		<u>188,125</u>	<u>7,742</u>	<u>195,867</u>	<u>208,546</u>
FUNDS					
Unrestricted funds	13			188,125	200,804
Restricted funds				<u>7,742</u>	<u>7,742</u>
TOTAL FUNDS					
				<u>195,867</u>	<u>208,546</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st March 2024.

The members have not required the company to obtain an audit of its financial statements for the year ended 31st March 2024 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET - continued
31ST MARCH 2024

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 28th September 2024 and were signed on its behalf by:

David Rogerson

.....
Mr D A Rogerson - Trustee

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31ST MARCH 2024

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future, and on that basis the charity is considered to be a going concern.

The financial statements are prepared in sterling which is the functional currency of the entity, and are rounded to the nearest £1.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

In 2023/24 a number of significant grants were received towards the end of the financial year which clearly related to activities and expenditure covering the following financial year. The accounting policy is to reflect any income received which clearly relates to future years to be shown as Deferred Income in the Balance Sheet. In 2023/24 a figure of £36,000 has been recorded in Creditors as Deferred Income (22/23 £43,345).

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery	- 25% and 50% on cost
Fixtures and fittings	- 25% and 50% on cost
Computer equipment	- 25% and 50% on cost

The charity does not capitalise fixed assets costing less than £500.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK Corporation Tax purposes. Accordingly the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

1. ACCOUNTING POLICIES - continued

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals payable under operating leases are charged to the Statement of Financial Activities in the year in which they are payable.

Pensions

The pension cost charge represents the contribution payable by the Charity to the employers' defined contribution pension scheme.

Judgements and key sources of estimation uncertainty

In the application of the charity's accounting policies, the charity is required to make judgments, estimates and assumptions about the carrying value of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised, if the revision affects only that period, or in the period of the revision and future periods if the revision affects both the current and future periods.

There are no estimates and assumptions that are considered to have a significant risk of causing a material adjustments to the financial statements in a future period.

Financial instruments

The charity has only financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and are subsequently measured at their settlement value with the exception of bank loans which are measured at amortised cost using the effective interest method.

Financial Assets

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any discounts due.

Financial Liabilities

Creditors and provisions are recognised where the charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably. Creditors and provisions are normally recognised at their settlement amount after allowing for any discounts due.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

2. DONATIONS AND LEGACIES

	2024	2023
	£	£
Donations	205,304	187,016
Grants	<u>94,468</u>	<u>170,674</u>
	<u>299,772</u>	<u>357,690</u>

Grants received, included in the above, are as follows:

	2024	2023
	£	£
Bartle Family Charitable Trust	1,000	1,000
BBC Children in Need	43,345	34,191
St James' Place Foundation	2,500	-
David Solomon Charitable Trust	750	-
The Wixamtree Trust	-	5,000
The Baily Thomas Charitable Fund	20,000	-
The Edgar Lee Foundation	1,350	500
The Woodroffe Benton Foundation	2,000	-
Masonic Charitable Foundation	-	5,000
CAF	-	85,797
Focus Foundation	-	5,000
Kilywalk	-	3,690
WGCGC	-	3,100
Markell	-	750
Design 4	-	3,750
The Big Give Christmas Challenge 2022	-	22,896
Tower Bridge	13,503	-
Priavo Security	1,020	-
Kaye Charitable Trust	1,000	-
MK Charitable trust	2,000	-
Michael Cornish Charitable Trust	1,000	-
The D'Oyly Carte Charitable Trust	4,000	-
ICECO Limited	<u>1,000</u>	<u>-</u>
	<u>94,468</u>	<u>170,674</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

3. OTHER TRADING ACTIVITIES

	2024	2023
	£	£
Sales	173	2,328
Unity Lottery and 300 Club	4,436	4,215
Other receipts	<u>1,264</u>	<u>684</u>
	<u>5,873</u>	<u>7,227</u>

4. INVESTMENT INCOME

	2024	2023
	£	£
Deposit account interest	<u>236</u>	<u>155</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2024	2023
	£	£
Independent Examiner	<u>2,405</u>	<u>2,285</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31st March 2024 nor for the year ended 31st March 2023.

Trustees' expenses

Travel expenses amounting to £nil (2023: £408) were reimbursed to no (2023: 2) Trustees

7. STAFF COSTS

	2024	2023
	£	£
Wages and Salaries	175,919	171,827
Social Security	12,417	18,286
Employers' Pension	<u>2,827</u>	<u>2,247</u>
	191,163	192,560
Other Staff Costs	<u>48,164</u>	<u>52,962</u>
	<u>239,327</u>	<u>245,522</u>

The average monthly number of employed personnel during the year was:

2024	2023
------	------

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

7. STAFF COSTS - continued

Average number	<u>6</u>	<u>5</u>
On a full time equivalent basis	<u>5</u>	<u>4</u>

There are also self employed personnel equating to a further 1 (2023: 1) member on a full time equivalent basis.

Key Management personnel (being the Trustees and the Chief Executive Officer) remuneration (comprising gross salary, employers' national insurance and employers' pension) amounted to £56,148 (2023: £55,056)

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	323,499	34,191	357,690
Other trading activities	7,227	-	7,227
Investment income	<u>155</u>	<u>-</u>	<u>155</u>
Total	<u>330,881</u>	<u>34,191</u>	<u>365,072</u>
EXPENDITURE ON			
Raising funds	79,666	-	79,666
Charitable activities			
Charitable activities	<u>239,992</u>	<u>34,191</u>	<u>274,183</u>
Total	<u>319,658</u>	<u>34,191</u>	<u>353,849</u>
NET INCOME	11,223	-	11,223
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>189,581</u>	<u>7,742</u>	<u>197,323</u>
TOTAL FUNDS CARRIED FORWARD	<u>200,804</u>	<u>7,742</u>	<u>208,546</u>

RETT UK
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NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

9. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1st April 2023 and 31st March 2024	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
DEPRECIATION				
At 1st April 2023 and 31st March 2024	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
NET BOOK VALUE				
At 31st March 2024	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
At 31st March 2023	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Trade debtors	150	-
Prepayments	<u>16,464</u>	<u>19,322</u>
	<u>16,614</u>	<u>19,322</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Other creditors	-	2,190
Accruals and deferred income	<u>38,280</u>	<u>43,345</u>
	<u>38,280</u>	<u>45,535</u>

12. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2024 £	2023 £
Within one year	912	1,824
Between one and five years	<u>912</u>	<u>912</u>
	<u>1,824</u>	<u>2,736</u>

RETT UK
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NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

13. MOVEMENT IN FUNDS

	At 1/4/23 £	Net movement in funds £	At 31/3/24 £
Unrestricted funds			
General fund	200,804	(12,679)	188,125
Restricted funds			
Research Fund	7,742	-	7,742
TOTAL FUNDS	<u>208,546</u>	<u>(12,679)</u>	<u>195,867</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	305,881	(318,560)	(12,679)
TOTAL FUNDS	<u>305,881</u>	<u>(318,560)</u>	<u>(12,679)</u>

Comparatives for movement in funds

	At 1/4/22 £	Net movement in funds £	At 31/3/23 £
Unrestricted funds			
General fund	189,581	11,223	200,804
Restricted funds			
Research Fund	7,742	-	7,742
TOTAL FUNDS	<u>197,323</u>	<u>11,223</u>	<u>208,546</u>

RETT UK
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NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2024

13. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	330,881	(319,658)	11,223
Restricted funds			
BBC Children in Need	34,191	(34,191)	-
TOTAL FUNDS	<u>365,072</u>	<u>(353,849)</u>	<u>11,223</u>

Research Funds

All monies in the Research Funds are utilised to support possible treatments and cures.

14. EMPLOYEE BENEFIT OBLIGATIONS

The charitable company operates a defined contribution pension scheme with contributions being made by both employer and employees at variable rates. Total pension costs in the current year amounted to £2,827 (2023: £2,247). At the year end £nil was due to the provider (2023: £nil).

15. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31st March 2024.

E J Le-Warde, a Trustee, is the son of a member of staff.

RETT UK
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DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31ST MARCH 2024

	2024 £	2023 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	205,304	187,016
Grants	<u>94,468</u>	<u>170,674</u>
	299,772	357,690
Other trading activities		
Sales	173	2,328
Unity Lottery and 300 Club	4,436	4,215
Other receipts	<u>1,264</u>	<u>684</u>
	5,873	7,227
Investment income		
Deposit account interest	<u>236</u>	<u>155</u>
Total incoming resources	305,881	365,072
EXPENDITURE		
Raising donations and legacies		
Wages	47,677	47,204
Insurance	541	1,239
Telephone	102	438
Postage and stationery	1,526	1,292
Purchases for resale	1,243	3,064
Magazine, booklet and information	4,223	6,258
Event operations	11,857	9,670
IT	1,578	7,824
Premises	1,440	1,531
Other	<u>3,314</u>	<u>1,146</u>
	73,501	79,666
Charitable activities		
Wages	191,509	192,505
Insurance	1,262	2,886
Telephone	1,364	2,274
Carried forward	194,135	197,665

This page does not form part of the statutory financial statements

RETT UK
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DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31ST MARCH 2024

	2024	2023
	£	£
Charitable activities		
Brought forward	194,135	197,665
Postage and stationery	3,814	3,994
Sundries	3,555	5,935
Magazine, booklet and information	11,718	8,724
Family weekend & regional day	1,710	7,126
Rent and property expenses	6,147	6,125
Repairs & maintenance	2,290	1,718
IT	10,536	29,937
Travel	4,518	3,943
Bank charges	1,464	1,410
Other Staff costs	<u>2,767</u>	<u>5,321</u>
	242,654	271,898
Support costs		
Governance costs		
Independent Examiner's fees	<u>2,405</u>	<u>2,285</u>
Total resources expended	<u>318,560</u>	<u>353,849</u>
Net (expenditure)/income	<u>(12,679)</u>	<u>11,223</u>

This page does not form part of the statutory financial statements

RETT UK

England & Wales - Charity number 1137820

Accounts

REGISTERED COMPANY NUMBER: 7339522 (England and Wales)
REGISTERED CHARITY NUMBER: England and Wales: 1137820, Scotland: SCO47369

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST MARCH 2023
FOR
RETT UK
(A COMPANY LIMITED BY GUARANTEE)

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

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FOR THE YEAR ENDED 31ST MARCH 2023

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It has been a busy year for Rett UK and a successful one. The external environment continues to be challenging, with the cost-of-living crisis following hard on the heels of the pandemic, putting more strain on Rett families while also making it harder for charity to raise funds to support them. Internally the organisation has also faced challenges with several changes in personnel both within the Board and the staff team. Despite all of this, Rett UK has continued to maintain and even expand the support provided to Rett families this year. This is a compliment to the hard-work and expertise of Rob Adamek and the whole team of staff and volunteers that keeps Rett UK ticking along. My heart-felt thanks to every one of you.

I would like to thank Hilary Truss, my predecessor as Chair of Trustees, who stepped down at the December 2022 Board meeting. Hilary led the charity with knowledge, passion and commitment for 7 years, steering us through some challenging times and leaving such a well-run organisation that my job these past nine months has largely been straight forward, continuing on the course that Hilary had already set for the Charity.

There have, however, been changes on the Board of Trustees. We have welcomed two new trustees this year: Debbie Cavaldaro and Dolores Cowburn. Not only do they bring expertise in governance, communications and public relations, but we now also have a gender-balanced board – which is surely appropriate for a charity that deals with a syndrome primarily affecting females. As we welcome each one of them, we also say goodbye and thank you to Ali Sadek who leaves the Board to concentrate on his work as a lawyer, a local councillor and a new father.

Following the pandemic, it has taken time to rebuild income from events whether organised by Rett UK or external events such as the London Marathon. However, I am pleased to report that the income in 2022/23 has now bounced back above pre-pandemic levels, so a very big thank you to everyone who ran, walked, cycled, baked etc for Rett UK this past year – over £100,000 was raised through events this year (including an extraordinary 27 Rett UK participants in the Great North Run). Most amazingly, income raised through grants and trusts (including £74,000 carried forward from last year's major CAF grant) was double that achieved in 2019-20 – a tremendous achievement!

Success in fundraising enables us to achieve much more in support of Rett families. The family support team of Julie Benson and Donna Tinch has handled 2318 individual cases this year covering 877 families which is a tremendous achievement for such a small team. Our ground-breaking communications programme continues to go from strength to strength, led by Gill Townend, Abigail Davison Holt and Tracey Campbell, ably supported by a network of Regional Communications Champions. This year a more structured approach of individual assessments, clinics, training sessions and webinars has been developed, bringing more people into the programme and working to enhance the skills of those who have been using eye-gaze devices and other tools for several years.

This year we have also been able to invest in our IT systems. This is vital to ensuring the smooth-running of the organisation as it grows and develops. If you haven't already done so, please log-on and see the changes at www.rettuk.org.

Looking forward, Rett UK is planning a big Family Weekend in October 2024 and has started to raise the required funds. The Charity is continuing to develop its links with Reverse Rett and exploring ways the two charities can work together as we enter an exciting phase of clinical development and gene therapy treatments. These advances are to be welcomed and celebrated, although I think we should remain cautious until there is evidence-based research to demonstrate their efficacy and safety. However, the primary work of Rett UK will continue to be supporting the day-to-day needs of Rett families and providing the resources to maximise the life experience of each individual with Rett syndrome. That is why we are here, and why it is so pleasing to be able to report on the progress we have made during the 2022-23 year.

David Rogerson
Chair of Trustees

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st March 2023. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

About Rett Syndrome

Rett UK is the national charity dedicated to supporting and empowering people with Rett syndrome and their families. Imagine being told the toddler you thought was healthy, but perhaps slow to progress, in fact had a rare and devastating disability that would leave them needing lifelong 24/7 care. That is the reality for parents receiving a diagnosis of Rett syndrome for their child.

Although present at birth, Rett syndrome is usually undetected until a major regression occurs at around two years of age. Children lose acquired skills and the complexity of the disability is revealed. Rett syndrome is a severe, life long, life limiting genetic neurological disorder; the most common cause of profound disabilities affecting females (1 in 10,000).

Our services empower families, build their emotional resilience, support positive relationships within the family and help reduce isolation improving the health and well-being of all family members including the person with Rett syndrome. When your GP has never heard of it and the paediatrician only recalls reading about it in a text book, the families feel they are in a black hole. Access to high quality information, advice and support is not only vital but life changing.

Our national telephone helpline is the first point of call for desperately worried parents, not just at the point of diagnosis but at moments of crisis; a sudden deterioration in their daughter's health, cuts to respite and care packages, bereavement. We advocate on their behalf especially for education, communication training and therapy services.

Local family led support groups, a parent-to-parent contact network, access to high quality seminars from the UK's leading experts on Rett syndrome at Regional Roadshows and Family Weekends and, more recently, online provides families with up to date, accurate information in subjects like epilepsy, spinal surgery, sleep and breathing, helping them with management of the disability. We also have a dedicated project helping people with Rett syndrome to maximise their communication potential and provide support, training and advice to parents, care providers and a UK wide network of speech and language therapists who are working with individual who have Rett syndrome.

Objectives and aims

Our purpose...

Rett UK is a national charity dedicated to supporting and empowering people with Rett syndrome, their families and those involved in providing their care. We are a membership organisation and welcome members from the UK and abroad.

Our strategic aims are to ...

- provide professional family-support services, activities and events at a local, regional and national level
- educate health, social care and education professionals about Rett syndrome to enable quicker diagnosis and improved standards of care throughout the UK
- advocate for people with Rett syndrome to be given the support and resources needed to be active communicators
- promote, support and encourage research into new therapies and treatments for Rett syndrome Our vision...

That everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

RETT UK
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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

OBJECTIVES AND ACTIVITIES

Public benefit

In shaping our objectives and planning our activities for the year, the Trustees have given consideration to the duties set out in section 17(5) of the Charities Act 2011 to have due regard to public benefit and to the Charity Commission Guidance on public benefit. In particular, the Trustees have considered how the planned activities will contribute to the overall aims and objectives that they have set.

The Trustees believe that the paragraph, specifically on "Achievements and Performance" for the year, relate in detail the benefit that the charity provides to the public.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

This year has been far more uplifting in contrast to the previous one. We've remained steadfast in our commitment to consistently provide unwavering support to our cherished families and members of the Rett community. Over the year we completed numerous successful projects, including not one but two in-person events after a hiatus of two years.

Our engagement has extended to attending a multitude of meetings, where we've been able to stand beside families during their most difficult moments, offering relevant advocacy support. We also continued to connect families with a network of Rett professionals, fostering connections that might otherwise never have been made.

We end the year to 31st March 2023 with a surplus of £11,223 and a cash balance of £234,759.

Belfast Regional Weekend

We hosted a very successful event involving families from both the Republic and Northern Ireland. The primary focus was on enhancing communication, and the Rett UK AAC team, led by Gill, curated an outstanding program that was exceptionally well-received.

A parent who participated in the event shared: *"The strategies and insights I gained from the sessions have the potential to bring about profound changes in my family's life. I had doubts about whether it was feasible to start utilising communication devices at this point, but I was reassured that...it's never too late."*

The response was overwhelming, with numerous individuals seeking opportunities to engage with professionals. This demand was so substantial that we arranged a separate event featuring a Q&A panel, an opportunity we plan to extend to a wider audience.

Read, Write and Make Friends? Count us in!

We successfully introduced numeracy and literacy training, using our carefully chosen books that encourage engagement, questions and discussion for people with Rett syndrome. We also created dedicated communication partner training and online friendship groups for people of all ages to meet and practise their communication skills in a fun, relaxed way with their peers.

What we achieved with the project:

- More parent carers and other care givers now have confidence as communication partners. They are able to employ a diverse range of AAC strategies and tools when interacting with the individuals they support, adapting across various contexts.
- Individuals utilising advanced communication tools experience a significantly enhanced means of expression, employing diverse AAC methods across a multitude of environments.
- Enhanced communication modes have led to improved overall health and well-being for individuals using advanced AAC techniques, resulting in reduced frustration, anxiety, and heightened self-esteem. These individuals now approach communication with elevated confidence.
- Within educational settings, particularly schools and colleges, there's a remarkable rise in academic achievements, notably in areas such as literacy and numeracy, for those utilising advanced communication methods.
- People of all ages with diverse communication needs now experience decreased isolation, finding themselves readily participating in conversations with friends and becoming more effective self-advocates.

RETT UK
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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

Maximising the communication potential of people with Rett syndrome

A key area of activity of the charity is enabling those with Rett to communicate. We support people with Rett and those involved in their care with the use of eye gaze technology. This uses eye-tracking cameras and software on tablets that enables the users of the technology to communicate using their eyes. We provide training, loan of devices and support networks.

In the year we resumed face-to-face activities alongside providing an integrated array of online offerings, ensuring accessibility for families and professionals across the UK. Our digital offerings have transcended geographical boundaries, enabling participation from international families and professionals who have engaged in our activities and even invited us to contribute to online conferences held by Rett Associations in various countries. Despite our expanded reach, our foremost commitment remains dedicated to supporting families and professionals within the UK.

Communication Professionals Network

The Communication Professionals Network, established with the backing of Rett UK's proficient Communication and Education team, continues to thrive. This dynamic network caters to professionals engaged with individuals having Rett syndrome, regardless of their setting, age group, level of expertise, or geographical location within the UK.

Membership to this invaluable network involves a one-time enrolment fee, granting access to a wealth of exceptional resources and team-backed support, complemented by the provision of comprehensive communication guidelines. Alongside these benefits, each member receives a copy of the communication guidelines as a valuable reference. Explore the network's offerings and connect with like-minded professionals at www.rettuk.org/CPN.

Communication Device Loan Programme

We are extremely proud of our communication device loan programme. It provides the opportunity for people with Rett to trial the use of these amazing electronic devices whilst being fully supported by the communications team. This enables families and those supporting them to develop the cases needed to secure their own devices. This ultimately provides people with Rett their own voice.

The loan program operates within a well-defined structure, offering an initial 8-week term, extendable up to a total of 6 months. Every family benefits from dedicated assistance provided by a Regional Communications Coordinator (RCC). Each RCC is assigned to support two families, while a buddy system pairs two RCCs to collaborate closely.

To further enhance the experience for loan families, we've introduced a more comprehensive information sheet within the loan guide pack. This sheet elaborates on the weekly video submissions required. Our intention in aligning this structure with the decision flowchart used by NHS hubs for funding application readiness is to bolster the quality of evidence we receive from families. This strategic approach ensures that progress made with Augmentative and Alternative Communication (AAC) is effectively tracked and documented.

Family Feedback: "I want to express my heartfelt gratitude to you and everyone at Rett UK for granting us the chance to test out the eye gaze technology. Its value has been immeasurable, and I received confirmation from the Trust just yesterday that our application has been approved."

Education, Health and Care Plan support

Throughout the year, our dedicated team has experienced a remarkable surge in demand for EHCP assistance. We've been able to help a substantial number of families with both new and existing EHCP documents, extending our services to include participation as expert advocates during Annual Reviews. Furthermore, where possible we have extended our support to professionals in both specialized and mainstream schools, delving into the realms of communication and Rett syndrome.

The surge in demand underscores the crucial necessity of our service. Many families are seeking clarity regarding EHCPs, their purpose, entitlements, and the various timeframes embedded within the process. We've come to realise that there exists a genuine need for comprehensive guidance, as families often find themselves uncertain about their authority in shaping the document's content.

Friendship groups

The adult (16+) friendship group is now an established part of our events calendar and continues to meet online on a monthly basis. We continue to innovate in the groups as we continue to explore how we can work directly with people with Rett syndrome, to develop advocacy skills, and listen to what they tell us, we see the members of this adult group as important contributors to helping us shape the services and support we offer.

Regional Communication Champions

We currently hold a monthly meeting for RCC discussions, supplemented by additional meetings when necessary. These additional meetings are primarily intended for providing training to create resources and to offer assistance to the newly appointed RCCs. We are thrilled by the seamless integration of the new members of the team and their remarkable level of engagement. The mentorship dynamic between the veterans and the new team members is proving to be effective, as the newcomers have actively participated in resource generation and have also gained hands-on experience through their involvement in the loan program.

Additionally, we continue actively seeking to expand our team of RCCs to areas that are currently not covered, in order to extend our reach and provide support to even more individuals affected by Rett syndrome.

Comments from people using the service

About the loan programme: "Absolutely transformative! The loan programme delivered the crucial solution we required for our daughter, as well as for her school and communication associates. It allowed everyone to genuinely comprehend her voice, marking a significant milestone."

Parent of a recently diagnosed child: "I am immensely grateful! It's hard to imagine where I'd be without your support."

Local Authority SEN Officer: "Expressing my gratitude for the valuable and much-appreciated information you shared during the meeting."

Connecting Families and Reducing Isolation

During the year our membership continued to rise again to over 3657 people.

Our Family Support team's national telephone helpline remains the primary point of contact for individuals affected by Rett syndrome. The demand for assistance continues to surge, with an increasing number of families initially reaching out through social media platforms and subsequently becoming members, thereby gaining access to the full spectrum of support services we offer.

Each quarter witnesses an overwhelming engagement, totalling more than 700 interactions with family members. These interactions encompass calls to our helpline, communications via our support email, direct correspondence, responses on Facebook, WhatsApp, Twitter, Instagram, and Facebook Messenger.

These points of contact serve diverse purposes, ranging from seeking information about Rett syndrome or specific symptoms to emotionally charged calls from families grappling with a new diagnosis. As their intensity and duration vary, our dedicated family support team is equipped with extensive skills and training to address each call effectively. They provide comfort, empathy, guidance, advice, and pertinent information, understanding the unique needs of every individual who reaches out to us.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

The demand for our services continues to grow, and we are committed to meeting it by continually bolstering our resources and expertise wherever necessary.

Family Feedback

We're delighted to share some of the heart-warming feedback we've received from the families we've had the privilege to support. These messages highlight the positive impact of our efforts and serve as a reminder of why our work is so meaningful.

"Can you believe it? That appeal did the trick, and they've agreed to provide the equipment that she needs. We seriously can't thank you enough for being such a huge help in making this happen. You've been amazing throughout this whole process. When we were feeling totally lost and desperate, not knowing where to turn, your offer to assist was like a breath of fresh air. It felt like a massive weight was lifted off our shoulders."

"Just wanted to let you know they are starting work next Monday! Woohoo! That email you helped us put together for our daughter worked like magic. Your support and effort mean a lot to us, and we're super thankful. You're making a real difference in our lives, and we can't thank you enough!"

Dads' Online Meetups

With the valuable contributions of two of our Regional Community Coordinators (RCCs), the Beer & Banter sessions were launched. Scheduled every six weeks, Beer & Banter presents a unique opportunity for fathers to gather, share a drink of their choice, and engage in conversations about the intricacies of fatherhood. As part of our ongoing efforts to support fathers, we have also established an exclusive Facebook group tailored to their needs. This dedicated space allows members to post inquiries, connect with our team for practical insights, and receive prompt responses to their questions.

In our commitment to fostering a thriving community, we are actively exploring ways to enhance our offerings and encourage more members to join these meaningful discussions. Participation and feedback are instrumental in shaping these positive changes. For further information, please visit: <https://www.facebook.com/groups/ukrettdads>

Partnerships, Alliances, Campaigning and Awareness Raising

As we continue our partnership with Reverse Rett under the RDA banner, we recognize the paramount significance of unity in the face of evolving medical advancements and technological breakthroughs. Collaborating closely not only enhances our collective understanding but also ensures that as novel medicines emerge and technology progresses, we are well-equipped to navigate these changes effectively. This shared endeavour enables us to remain at the forefront of support ensuring that the entire UK Rett community receives the maximum benefit from emerging treatments and cutting-edge technologies.

Disabled Children's Partnership

As members of the partnership, we were involved in the following campaigns over the course of the year:

- the SEND Green Paper review
- Lockdown isn't over for us all report
- parental survey 1,848 responses so far
- Make your voice heard by the new Minister for Schools and Childhood campaign

The DCP "Give It Back" campaign with The Sun which won the News Media Association's Make a Difference award.

We are also now part of the newly re-formed Public Affairs Group Meeting which has a focus on trying to engage with politicians to get things achieved. This looks like it has got off to a good start with commitments from senior Labour party members willing to engage immediately

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

Rett UK is also a member of The Helplines Partnership, Genetic Alliance UK, Embracing Complexity, The NVCO, Bedfordshire Chamber of Commerce and takes an active role in The Disabled Children's Partnership Campaign to highlight the challenges faced by families who have children with disabilities.

NHS Clinics

Our specialised Rett clinics operate across four locations: Cardiff, Manchester, London, and Nottingham. Three of these clinics have returned to their regular schedules, with Manchester and Nottingham offering in-person appointments. London, on the other hand, has opted to continue conducting clinics virtually, a choice that has proven effective for families scattered across the UK. This approach minimizes travel-related disruptions for families and their children. The added advantage of observing the child in their familiar environment has yielded positive results. In situations where clinic team members deem an in-person meeting necessary, such appointments will be arranged, ensuring face-to-face assessments for families. The Cardiff clinic is yet to convene, primarily due to space limitations rather than a lack of referrals. Nevertheless, discussions are ongoing to plan future face-to-face clinics.

The London team is witnessing a rise in patients seeking clinical diagnoses, driven by heightened demand from local paediatricians and geneticists for whole genome sequencing. While this method holds immense value, it can take between 1 year and 18 months to complete, leaving families without a confirmed diagnosis during this period.

This service proves invaluable for families struggling to find local experts with knowledge of this rare disorder. We persist in exploring avenues to enhance the capabilities of these clinics.

We also support referrals to the CIPP Rett Centre. Which is a clinical treatment and research centre for children and adults with Rett Syndrome and related disorders of all ages based at King's College Hospital, funded by Reverse Rett.

Rett UK remains dedicated to making a meaningful impact on families grappling with the daily challenges posed by Rett syndrome. Our efforts encompass various dimensions, from alleviating the isolation these families often experience, to empowering them as effective advocates for their children. We focus on bolstering their emotional resilience, enhancing their overall well-being, fostering positive intra-family relationships, and ensuring they access the entitled benefits to optimize their family's financial stability. Through these initiatives, Rett UK is actively shaping a brighter future for those affected by this devastating disorder

FINANCIAL REVIEW

Principal funding sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Investment policy and objectives

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary / advisor who is authorised by the FCA. Recommendations will be brought to the Board of Trustees at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to The Board of Trustees, normally by e-mail, for comment/agreement within 7 days.

Rett UK's investments currently comprise cash held on deposit with Hampshire Trust Bank. This enables easy and speedy access to funds and reflects the Board's low risk approach to investments.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

FINANCIAL REVIEW

Reserves policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months' running costs, calculated against the current year's budgeted general expenditure. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations. In addition reserves are held where funds are raised for dedicated projects. Reserves are higher at 31 March 2023 as funding has been earmarked for national Family Weekend in 2024. It is anticipated that further funding will be raised in the year to support this key event. The higher than normal level of reserves also anticipates costs earmarked for a planned Family Weekend in 2024.

Rett UK will regularly monitor its reserves via the Honorary Treasurer and CEO who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year. The Finance Committee will bring any recommendations or observations to the Board of Trustees at the following meeting.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a company limited by guarantee, incorporated on 9 August 2010 and registered as a charity on 6 September 2010.

The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed by its Articles of Association. Copies of the Articles of Association are available at www.rettuk.org or from its Head Office by request.

The charity was formed to continue the work of Rett Syndrome Association UK (working name RSAUK) a charity registered in 1986, and given a more succinct name.

The members have guaranteed to contribute a maximum of £10 each in the event of the company being wound up.

Organisational structure

The charity is run by a management committee comprising the trustees and co-opted members, who delegate the day to day running to the Chief Executive Officer, Robert Adamek.

Appointment, and Induction and training of new trustees

The Directors are Charity Trustees as defined by section 177 of the Charities Act 2011. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Internal Control and Risk management

The Board of Trustees is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the CEO who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a three-year Business Plan written by the CEO and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules which the Charity faces, the Board of Trustees confirms that systems have been established to minimise organisational and financial risks.

The Board of Trustees has established two sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees.

The Finance Committee, Chaired by the Treasurer, discusses and agrees the annual budget (including approving salary reviews) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary / adviser who is authorised by the FCA. It reviews the annual audit plan of the external organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

The Management Committee reviews and discusses personnel and general management issues before making recommendations to the Board of Trustees. It also has responsibility for reviewing the policies and procedures of Rett UK; the majority are reviewed every three years with the exception of The Safeguarding Children and Vulnerable Adults Policy, The Finance Policy and The Reserves Policy which are reviewed annually. Other policies may be reviewed when a change in legislation or guidance necessitates it.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

7339522 (England and Wales)

Registered Charity number

1137820 (England and Wales)

SCO47369 (Scotland)

Registered office

Victory House
Chobham Street
Luton
Bedfordshire
LU1 3BS

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

Trustees

Ms H Truss (resigned 10/12/2022)
Mr R H Valentine (resigned 8/8/2022)
Mr M Britten
Mr P R Gander
Mr D A Rogerson
Mr C R Beadle
Mrs J Campobello
Mr S Ledger
Mrs P S Bardon
Mr G Lawson (resigned 24/9/2022)
Mr A Sadek (resigned 19/7/2023)
E J Le-Warde

Independent Examiner

Shona Wardrop CA
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Bankers

HSBC
Ballards Lane
Church End
Finchley
London
N3 2BH

Metro Bank plc
One Southampton Row
London
WC1B 5HA

Hampshire Trust Bank plc
PO Box 74003
London
EC2P 2QR

Patrons

Yvonne Milne MBE
Ann Clwyd MP
Evelyn Glennie DBE
Gloria Hunniford
Jon Snow
Victoria Murphy

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2023

STATEMENT OF TRUSTEES' RESPONSIBILITIES


The trustees (who are also the directors of Rett UK (A company limited by guarantee) for the purposes of company law) are responsible for preparing the Annual Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 2nd October 2023 and signed on its behalf by:



.....
Mr D A Rogerson - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
RETT UK
(A COMPANY LIMITED BY GUARANTEE)**

Independent examiner's report to the trustees of Rett UK (A company limited by guarantee) ('the Company')
I report to the charity trustees on my examination of the accounts of the Company for the year ended 31st March 2023.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under Section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under Section 145(5) (b) of the 2011 Act.

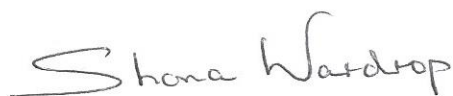
Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a member of the Institute of Chartered Accountants in England and Wales, which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by Section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of Section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Shona Wardrop CA

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Date: 30 | 10 | 23

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31ST MARCH 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	323,499	34,191	357,690	303,312
Other trading activities	3	7,227	-	7,227	5,516
Investment income	4	155	-	155	289
Other income		-	-	-	10,641
Total		<u>330,881</u>	<u>34,191</u>	<u>365,072</u>	<u>319,758</u>
EXPENDITURE ON					
Raising funds		79,666	-	79,666	71,935
Charitable activities					
Charitable activities		<u>239,992</u>	<u>34,191</u>	<u>274,183</u>	<u>239,507</u>
Total		<u>319,658</u>	<u>34,191</u>	<u>353,849</u>	<u>311,442</u>
NET INCOME		11,223	-	11,223	8,316
RECONCILIATION OF FUNDS					
Total funds brought forward		189,581	7,742	197,323	189,007
TOTAL FUNDS CARRIED FORWARD		<u>200,804</u>	<u>7,742</u>	<u>208,546</u>	<u>197,323</u>

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET
31ST MARCH 2023

	Notes	Unrestricted funds £	Restricted funds £	2023 Total funds £	2022 Total funds £
CURRENT ASSETS					
Debtors	10	19,322	-	19,322	11,651
Cash at bank		<u>227,017</u>	<u>7,742</u>	<u>234,759</u>	<u>272,598</u>
		246,339	7,742	254,081	284,249
CREDITORS					
Amounts falling due within one year	11	(45,535)	-	(45,535)	(86,926)
		<u>200,804</u>	<u>7,742</u>	<u>208,546</u>	<u>197,323</u>
NET CURRENT ASSETS					
		<u>200,804</u>	<u>7,742</u>	<u>208,546</u>	<u>197,323</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>200,804</u>	<u>7,742</u>	<u>208,546</u>	<u>197,323</u>
NET ASSETS					
		<u>200,804</u>	<u>7,742</u>	<u>208,546</u>	<u>197,323</u>
FUNDS					
	13			200,804	189,581
Unrestricted funds				<u>7,742</u>	<u>7,742</u>
Restricted funds					
TOTAL FUNDS					
				<u>208,546</u>	<u>197,323</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st March 2023.

The members have not required the company to obtain an audit of its financial statements for the year ended 31st March 2023 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

BALANCE SHEET - continued
31ST MARCH 2023

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 2nd October 2023 and were signed on its behalf by:



.....
Mr D A Rogerson - Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31ST MARCH 2023

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future, and on that basis the charity is considered to be a going concern.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

In 2022/23 a number of significant grants were received towards the end of the financial year which clearly related to activities and expenditure covering the following financial year. The accounting policy is to reflect any income received which clearly relates to future years to be shown as Deferred Income in the Balance Sheet. In 2022/23 a figure of £43,345 has been recorded in Creditors as Deferred Income (21/22 £77,146).

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery	- 25% and 50% on cost
Fixtures and fittings	- 25% and 50% on cost
Computer equipment	- 25% and 50% on cost

The charity does not capitalise fixed assets costing less than £500.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK Corporation Tax purposes. Accordingly the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

1. ACCOUNTING POLICIES - continued

Fund accounting

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals payable under operating leases are charged to the Statement of Financial Activities in the year in which they are payable.

Pensions

The pension cost charge represents the contribution payable by the Charity to the employers' defined contribution pension scheme.

2. DONATIONS AND LEGACIES

	2023	2022
	£	£
Donations	187,016	167,340
Grants	<u>170,674</u>	<u>135,972</u>
	<u>357,690</u>	<u>303,312</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

2. DONATIONS AND LEGACIES - continued

Grants received, included in the above, are as follows:

	2023	2022
	£	£
Bartle Family Charitable Trust	1,000	1,000
BBC Children in Need	34,191	31,518
The Wixamtree Trust	5,000	-
The Edgar Lee Foundation	500	1,250
Masonic Charitable Foundation	5,000	5,000
Demelza Hospice	-	18,300
The February Foundation	-	5,000
The Big Give Christmas Challenge 2021	-	18,756
Awards for All	-	9,802
The Hargreaves Foundation	-	6,722
The Pears Foundation	-	6,930
Arnold Clark	-	1,000
The Edward Gostling Foundation	-	5,000
Abingdon Freewheel	-	694
CAF	85,797	25,000
Focus Foundation	5,000	-
Kilywalk	3,690	-
WGCGC	3,100	-
Markell	750	-
Design 4	3,750	-
The Big Give Christmas Challenge 2022	<u>22,896</u>	<u>-</u>
	<u>170,674</u>	<u>135,972</u>

3. OTHER TRADING ACTIVITIES

	2023	2022
	£	£
Sales	2,328	584
Unity Lottery and 300 Club	4,215	3,366
Other receipts	<u>684</u>	<u>1,566</u>
	<u>7,227</u>	<u>5,516</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

4. INVESTMENT INCOME

	2023	2022
	£	£
Deposit account interest	<u>155</u>	<u>289</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2023	2022
	£	£
Independent Examiner	<u>2,285</u>	<u>2,213</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31st March 2023 nor for the year ended 31st March 2022.

Trustees' expenses

Travel expenses amounting to £408 (2022: £nil) were reimbursed to 2 Trustees

7. STAFF COSTS

	2023	2022
	£	£
Wages and Salaries	171,827	156,230
Social Security	18,286	15,454
Employers' Pension	<u>2,247</u>	<u>2,259</u>
	192,560	173,943
Other Staff Costs	<u>52,962</u>	<u>57,294</u>
	<u>245,522</u>	<u>231,237</u>

The average monthly number of employed personnel during the year was:

	2023	2022
Average number	<u>5</u>	<u>5</u>
On a full time equivalent basis	<u>4</u>	<u>4</u>

There are also self employed personnel equating to a further 1 (2022: 1) member on a full time equivalent basis.

Key Management personnel remuneration amounted to £55,056 (2022: £48,471)

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	271,794	31,518	303,312
Other trading activities	5,516	-	5,516
Investment income	289	-	289
Other income	<u>10,641</u>	<u>-</u>	<u>10,641</u>
Total	<u>288,240</u>	<u>31,518</u>	<u>319,758</u>
EXPENDITURE ON			
Raising funds	71,935	-	71,935
Charitable activities			
Charitable activities	<u>207,989</u>	<u>31,518</u>	<u>239,507</u>
Total	<u>279,924</u>	<u>31,518</u>	<u>311,442</u>
NET INCOME	8,316	-	8,316
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>181,265</u>	<u>7,742</u>	<u>189,007</u>
TOTAL FUNDS CARRIED FORWARD	<u>189,581</u>	<u>7,742</u>	<u>197,323</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

9. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1st April 2022 and 31st March 2023	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
DEPRECIATION				
At 1st April 2022 and 31st March 2023	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
NET BOOK VALUE				
At 31st March 2023	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
At 31st March 2022	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade debtors	-	948
Prepayments	<u>19,322</u>	<u>10,703</u>
	<u>19,322</u>	<u>11,651</u>

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2023 £	2022 £
Trade creditors	-	7,650
Other creditors	2,190	2,130
Accruals and deferred income	<u>43,345</u>	<u>77,146</u>
	<u>45,535</u>	<u>86,926</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

12. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2023	2022
	£	£
Within one year	1,824	1,824
Between one and five years	<u>912</u>	<u>2,736</u>
	<u>2,736</u>	<u>4,560</u>

13. MOVEMENT IN FUNDS

	At 1/4/22	Net movement in funds	At 31/3/23
	£	£	£
Unrestricted funds			
General fund	189,581	11,223	200,804
Restricted funds			
Research Fund	7,742	-	7,742
	<u>197,323</u>	<u>11,223</u>	<u>208,546</u>

Net movement in funds, included in the above are as follows:

	Incoming resources	Resources expended	Movement in funds
	£	£	£
Unrestricted funds			
General fund	330,881	(319,658)	11,223
Restricted funds			
BBC Children in Need	34,191	(34,191)	-
	<u>365,072</u>	<u>(353,849)</u>	<u>11,223</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

13. MOVEMENT IN FUNDS - continued

Comparatives for movement in funds

	At 1/4/21 £	Net movement in funds £	At 31/3/22 £
Unrestricted funds			
General fund	181,265	8,316	189,581
Restricted funds			
Research Fund	7,742	-	7,742
	<u>189,007</u>	<u>8,316</u>	<u>197,323</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	288,240	(279,924)	8,316
Restricted funds			
BBC Children in Need	31,518	(31,518)	-
	<u>319,758</u>	<u>(311,442)</u>	<u>8,316</u>

Research Funds

All monies in the Research Funds are utilised to support possible treatments and cures.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2023

14. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31st March 2023.

E J Le-Warde, a Trustee, is the son of a member of staff.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31ST MARCH 2023

	2023 £	2022 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	187,016	167,340
Grants	<u>170,674</u>	<u>135,972</u>
	357,690	303,312
Other trading activities		
Sales	2,328	584
Unity Lottery and 300 Club	4,215	3,366
Other receipts	<u>684</u>	<u>1,566</u>
	7,227	5,516
Investment income		
Deposit account interest	155	289
Other income		
Furlough grant	<u>-</u>	<u>10,641</u>
Total incoming resources	365,072	319,758
EXPENDITURE		
Raising donations and legacies		
Wages	47,204	43,699
Insurance	1,239	1,094
Telephone	438	170
Postage and stationery	1,292	1,109
Purchases for resale	3,064	3,213
Magazine, booklet and information	6,258	5,287
Event operations	9,670	10,240
IT	7,824	3,559
Premises	1,531	1,880
Other	<u>1,146</u>	<u>1,684</u>
	79,666	71,935

This page does not form part of the statutory financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

DETAILED STATEMENT OF FINANCIAL ACTIVITIES
FOR THE YEAR ENDED 31ST MARCH 2023

	2023	2022
	£	£
Charitable activities		
Wages	192,505	183,721
Insurance	2,886	1,997
Telephone	2,274	1,013
Postage and stationery	3,994	4,588
Sundries	5,935	3,293
Magazine, booklet and information	8,724	11,240
Family weekend & regional day	7,126	7,722
Rent and property expenses	6,125	7,964
Repairs & maintenance	1,718	3,113
IT	29,937	9,144
Travel	3,943	845
Bank charges	1,410	1,342
Other Staff costs	<u>5,321</u>	<u>1,312</u>
	271,898	237,294
Support costs		
Governance costs		
Independent Examiner's fees	<u>2,285</u>	<u>2,213</u>
Total resources expended	<u>353,849</u>	<u>311,442</u>
Net income	<u><u>11,223</u></u>	<u><u>8,316</u></u>

This page does not form part of the statutory financial statements

RETT UK

England & Wales - Charity number 1137820

Accounts

REGISTERED COMPANY NUMBER: 7339522 (England and Wales)
REGISTERED CHARITY NUMBER: England and Wales: 1137820, Scotland: SCO47369

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST MARCH 2022
FOR
RETT UK
(A COMPANY LIMITED BY GUARANTEE)

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

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FOR THE YEAR ENDED 31ST MARCH 2022

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RETT UK
(A COMPANY LIMITED BY GUARANTEE)

CHAIR'S REPORT
FOR THE YEAR ENDED 31ST MARCH 2022

I am pleased to report that during 2021-22 Rett UK has begun to resume business as usual since the pandemic. We have found, however, that some changes have been beneficial for our staff team and the majority of them now have their base at home and call into the office as and when they need to. This means that we are on the hunt to either downsize our current premises or move to another base.

We have begun to resume Family Days, but hope to have a mixture of in-person Family Days and online ones, as we are aware that an in-person Family Day often is not in a location accessible to our Rett families.

Two Trustees stepped down this year, Robert Valentine, who has been a loved and respected Trustee for many years and Celia Carter who has recently resumed full time work after the birth of her baby. We wish both of them well for the future.

I have decided that after nearly 7 years as Chair of Trustees it is time for me to hand over the reins to someone else. I am delighted to say David Rogerson has accepted the challenge and my last meeting will be in December 2022. I have really enjoyed my role and feel immensely proud of what we, the Rett community, staff, trustees and volunteers have achieved. Surviving a pandemic and emerging stronger is an amazing achievement for us all.

We have met the criteria for many trusts and foundations this year. This has been helped by the amazing work done with Robert Adamek as CEO and Becky Jenner as the person in charge of applying for trusts and grants, they have become an incredible team. We successfully bid for funding towards major projects from The Big Give, CAF (Charities Aid Foundation) and Children In Need. From some of this funding Robert has managed to start on updating our IT, data storage and website, which will hopefully make it easier for families with someone with Rett syndrome to access all the information they need. The rest continues to go on support for families and our communication projects.

Our communication work continues to be extremely popular, led by Gill Townend with Abigail Davison Holt and Tracey Campbell. Thank-you to all of the volunteers and paid regional communication champions (RCCs) who have helped with the free loan opportunities, friendship groups and general training with communication for the person with Rett syndrome. After many years of communication via a Yes/No card and a note book our 33 year old daughter had the opportunity of using an eye gaze machine. That was 4 years ago and she has never looked back. It was a real game changer for her.

Julie Benson continues to lead support for Rett UK, her time now divided between social media, online, in-person and telephone support. Donna Tinch leads on administration and the production of the magazine, which continues to be a popular part of what we offer.

Over the year our staff and volunteers have continued to be hard working and loyal members of the Rett UK team. I can't thank them enough for their commitment and loyalty.

Hilary Truss
Chair of Trustees

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st March 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

About Rett Syndrome

Imagine being told the toddler you thought was healthy, but perhaps slow to progress, in fact had a rare and devastating disability that would leave them needing lifelong 24/7 care. That is the reality for parents receiving a diagnosis of Rett syndrome for their child. Rett UK is the national charity dedicated to supporting and empowering people with Rett syndrome and their families.

Although present at birth, Rett syndrome is usually undetected until a major regression occurs at around two years of age. Children lose acquired skills and the complexity of the disability is revealed. Rett syndrome is a severe, life long, life limiting genetic neurological disorder; the most common cause of profound disabilities affecting females (1 in 10,000).

Our services empower families, build their emotional resilience, support positive relationships within the family and help reduce isolation improving the health and well-being of all family members including the person with Rett syndrome. When your GP has never heard of it and the paediatrician only recalls reading about it in a text book, the families feel they are in a black hole. Access to high quality information, advice and support is not only vital but life changing.

Our national telephone helpline is the first point of call for desperately worried parents, not just at the point of diagnosis but at moments of crisis; a sudden deterioration in their daughter's health, cuts to respite and care packages, bereavement. We advocate on their behalf especially for education, communication training and therapy services.

Local family led support groups, a parent-to-parent contact network, access to high quality seminars from the UK's leading experts on Rett syndrome at Regional Roadshows and Family Weekends and, more recently, online provides families with up to date, accurate information in subjects like epilepsy, spinal surgery, sleep and breathing, helping them with management of the disability. We also have a dedicated project helping people with Rett syndrome to maximise their communication potential and provide support, training and advice to a UK wide network of speech and language therapists who are working with individual who have Rett syndrome.

Objectives and aims

Our purpose...

Rett UK is a national charity dedicated to supporting and empowering people with Rett syndrome and their families. We are a membership organisation and welcome members from the UK and abroad.

Our strategic aims are to ...

- provide professional family-support services, activities and events at a local, regional and national level
 - educate health, social care and education professionals about Rett syndrome to enable quicker diagnosis and improved standards of care throughout the UK
 - advocate for people with Rett syndrome to be given the support and resources needed to be active communicators
 - promote, support and encourage research into new therapies and treatments for Rett syndrome
- Our vision...

That everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

OBJECTIVES AND ACTIVITIES

Public benefit

In shaping our objectives and planning our activities for the year, the Trustees have given consideration to the duties set out in section 17(5) of the Charities Act 2011 to have due regard to public benefit and to the Charity Commission Guidance on public benefit. In particular, the Trustees have considered how the planned activities will contribute to the overall aims and objectives that they have set.

The Trustees believe that the paragraph, specifically on "Achievements and Performance" for the year, relate in detail the benefit that the charity provides to the public.

ACHIEVEMENT AND PERFORMANCE

Charitable activities

Looking back over another difficult year, we can feel proud of all we have achieved to ensure that our families received the support that they have needed. We moved into a virtual world, where meetings and appointments are carried out via on various platforms, and for many families and carers this has been an unusual and steep learning curve. However, for the team, this move to a virtual environment has had some benefits. We have been able to attend more meetings and provide advocacy support to families, when they feel at their most vulnerable. We have also been able to surrounded them with Rett professionals, some of whom they may have never met.

We end the year with a surplus of £8,316 and a cash balance of £272,598 at 31 March 2022. We have achieved this financial position whilst continuing to support families through another difficult year.

Rett UK Advocacy, Achieving the Best Outcomes

To help advocate for better outcomes for people with Rett syndrome in health, social care and education we launched our Advocacy, Achieving the Best Outcomes project. It is fundamental to what we do. Families are exhausted by fighting a system that was already massively under-resourced, hard to navigate. COVID-19 has hugely exacerbated the issues and added to the crisis. The work has included:

- " Ensuring Children/young people with Rett syndrome are supported to achieve their best possible educational and developmental outcomes in the most appropriate setting with an Education, Health and Care Plan that it's fit for purpose.
- " Making sure people with Rett syndrome can achieve optimal health and well-being, with access to health services and social care services that provide appropriate treatment, therapies, equipment. Ensuring Social Care and NHS Continuing Health Care funding is being assessed and awarded correctly, and that the support provided is meeting needs.
- " Providing parent carers support in navigating the maze of health and social care services. They are getting the best out of what is available, and it meets the social, educational and health needs of their daughter/son.

Maximising the communication potential of people with Rett syndrome

Since the start of the pandemic all our activities have continued online. This has proved to be a good way of working and allowed us to change and improve some of the support mechanisms we offer to families. As we look ahead to we hope to be able to return to some face to face activities but anticipate continuing to offer many things online too, offering services irrespective of where families and professionals are based in the UK. Being online has also allowed families and professionals from abroad to join in with our activities and we have received requests to contribute to online conferences hosted by Rett Associations in other countries. Our main responsibility remains, however, to families and professionals in the UK.

Communication Professionals Network

We launched the network supported by Rett UK's Communication and Education team. The network is intended for all those who work with people with Rett syndrome, in any setting, with any age group and at any level of experience, in any region of the UK. Members pay a one-off fee to join the microsite and get access to some great resources and support from the team as well as a copy of the communication guidelines. www.rettuk.org/CPN

Rett Syndrome Communication Guidelines

The UK edition is available in print as well as digitally. As we were able to obtain a grant to cover printing costs, the print copy is available free of charge to families and is included in the one-off admin fee that communication professionals pay to sign up to the CPN. We are developing further guidelines implementation resources in collaboration with IRSF (formerly RSO).

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

Loan Device Programme

The loan programme has continued to grow and develop over the last year and we are very pleased with the online format of support we now offer. Loans are offered for an initial 8 weeks with the option to extend for a total of 6 months. Each family is supported by one Regional Communications Coordinator, with each RCC supporting two families and two RCCs paired together in a buddy scheme.

We have also now included in the guide pack for loan families a more detailed information sheet about the weekly videos that they need to send. We hope that this more structured layout which follows the decision flowchart held by NHS hubs for funding application readiness will enhance the evidence we obtain from families and charts progress made using AAC more effectively.

Family Feedback: "Thank you so much to yourself and all at Rett UK for giving us the opportunity to trial the use of eye gaze technology. It really has been invaluable and I had confirmation from the Trust yesterday that our application has been accepted and they are going to start fundraising for her!"

Discussion groups

Our discussion groups have continued into 2021/22 and we were delighted that Caroline Musselwhite joined us live for her session offering invaluable insight. We had over 50+ people attend live. The sessions have had some great feedback and were felt to be very valuable to all who attended.

EHCP support

Over the year the team has helped a significant number of families with new and existing EHCP documents, as well as attending Annual Reviews as expert advocate's. We have also offered support to professionals in both specialist and mainstream schools on the topics of both communication and Rett syndrome. It is evident that there is a need for this service, and that some families are not clear on the purpose of an EHCP, what it entitles them to, what the different timeframes within the process are, and how much authority they wield over finalising the document content.

Friendship groups

Our Friendship groups for children & adults with Rett syndrome took place throughout the year. The groups were separated into age groups and ran over six weeks covering a range of topics including musical preferences, the environment and fantastic woman who changed the world.

Regional Communication Champions

We continue to hold a monthly RCC Business meeting, with other meetings arranged as needed, for example, to offer training to make resources, to support the new RCCs. We are delighted with how well the new RCCs have integrated into the team and how active they are. The buddying between old and new RCCs is working well and the new RCCs have become active in making resources as well as shadowing the loan program.

This work continues to make a huge difference to many people with Rett syndrome and has a direct impact on their health and well-being.

Comments from families

"Thank you for all the help we have received from everyone and I look forward to Dani receiving her own device. The training meetings were so helpful and everyone who gave the time to help and support us and a huge thank you to our mental throughout the process." - Donna

"Thank you so much for this opportunity, we really found it very beneficial with establishing communication for X and will be continuing with the low tech until we are able to secure a device for her. The support from our RCC was amazing and the feedback was very helpful and we feel we have learnt much. Thank you again for the opportunity"

Connecting Families and Reducing Isolation

During the year our membership continued to rise again by 13% to over 2,849 people.

Our TESS service (Telephone Electronic Support Services) delivered by our Family Support team, remains the first port of call for those affected by this devastating disorder with more families making contact especially via social media in the first instance but then signing up to become members and accessing the full range of support services available.

Every quarter we have well over 600 individual points of contact with family members. These points of contact were through calls to our telephone helpline, via our support email, direct correspondence, Facebook responses, What's App, Twitter, Instagram and Facebook messenger.

Some of these calls may just be for information about Rett syndrome or a specific symptom, others will be highly charged emotional calls from newly diagnosed families so they vary in intensity and length of call but our family support team members are highly skilled and trained to deal with any call they receive and are able to offer comfort, support, empathy, guidance, advice and information.

Family Feedback

"We've just had a decision back from the transport department regarding our daughter's traditional school transport and they have agreed to provide it from our 2nd appeal, thank you so much for your help in this.

I honestly cannot thank you enough, for supporting us through this process, you are amazing. I was so grateful for your help in our hour of need, we were so desperate and didn't know who to turn to and when you said you would help it was like a weight had been lifted."

"Hi. Thank you for doing the letter. The company have just rung this afternoon and said they are starting the work on the bathroom next Monday. So, we would just like to say thank you for helping and writing the email on behalf of my daughter. We are very grateful.

Online Meetups

Following on from our successful Wine & Whinge and Coffee & Chat sessions, we decided it was time to introduce something for Dads too. So, with help from two of our RCC's the Beer & Banter sessions were created. Held every 6 weeks Beer & Banter is a unique opportunity for Dads to come together over a beer (or their favourite beverage) and talk about 'Dad Stuff'. We have also created a special Facebook group just for Dads too. Here you can post a question or contact one of the team who will help with practical tips and answer any questions. <https://www.facebook.com/groups/ukrettdads>

Partnerships, Alliances, Campaigning and Awareness Raising

We continue to advance our partnership with Reverse Rett under the RDA banner to best support the entire UK Rett community. As well as collaborative events, we have been working towards getting people registered on the Registry which will allow people to have access to information on trials and future Rett syndrome treatments including gene therapy.

Rett UK is also a member of The Helplines Partnership, Genetic Alliance UK, Embracing Complexity, The NVCO, Bedfordshire Chamber of Commerce and takes an active role in The Disabled Children's Partnership Campaign to highlight the challenges faced by families who have children with disabilities.

NHS Clinics

Our specialist Rett clinics which run at 4 locations (Cardiff, Manchester, London and Nottingham) struggled to continue operating throughout this difficult year. Manchester was the only clinic that have physically met since lockdown with the London clinic being the only clinic holding regular appointments virtually.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

This is an invaluable service to families who struggle to find someone who has a knowledge of the syndrome locally given the rarity of the disorder. We continue to explore ways to develop these clinics and, in particular, to have something similar for families in Scotland.

Rett UK continues to strive to make a difference to families living with the daily challenges of Rett syndrome; whether that is reducing the isolation they experience, empowering them to be the best advocates they can for their daughter or son, building their emotional resilience, improving their health and well-being and that of the person they care for, helping them maintain positive relationships within the family and ensuring they are able to maximise their family income from the benefits they are entitled to. Rett UK is giving a brighter future to anyone affected by this devastating disorder.

FINANCIAL REVIEW

Principal funding sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Investment policy and objectives

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary / advisor who is authorised by the FCA. Recommendations will be brought to the Board of Trustees at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to The Board of Trustees, normally by e-mail, for comment/agreement within 7 days.

Rett UK's investments currently comprise cash held on deposit with Hampshire Trust Bank. This enables easy and speedy access to funds and reflects the Board's low risk approach to investments.

Reserves policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months' running costs, calculated against the current year's budgeted general expenditure. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations.

At the end of the 2021 Financial Year the charity's unrestricted reserves amounted to 6 months of budget running costs which the trustees consider to be prudent in the short term in the light of the ongoing economic upheaval and uncertainties caused by the Covid pandemic and the war in Ukraine.

Rett UK will regularly monitor its reserves via the Honorary Treasurer and CEO who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year. The Finance Committee will bring any recommendations or observations to the Board of Trustees at the following meeting.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a company limited by guarantee, incorporated on 9 August 2010 and registered as a charity on 6 September 2010.

The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed by its Articles of Association. Copies of the Articles of Association are available at www.rettuk.org or from its Head Office by request.

The charity was formed to continue the work of Rett Syndrome Association UK (working name RSAUK) a charity registered in 1986, and given a more succinct name.

The members have guaranteed to contribute a maximum of £10 each in the event of the company being wound up.

Organisational structure

The charity is run by a management committee comprising the trustees and co-opted members, who delegate the day to day running to the Chief Executive Officer, Robert Adamek.

Appointment, and Induction and training of new trustees

The Directors are Charity Trustees as defined by section 177 of the Charities Act 2011. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

STRUCTURE, GOVERNANCE AND MANAGEMENT

Internal Control and Risk management

The Board of Trustees is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the CEO who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a three-year Business Plan written by the CEO and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules which the Charity faces, the Board of Trustees confirms that systems have been established to minimise organisational and financial risks.

The Board of Trustees has established two sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees.

The Finance Committee, Chaired by the Treasurer, discusses and agrees the annual budget (including approving salary reviews) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary / adviser who is authorised by the FCA. It reviews the annual audit plan of the external organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

The Management Committee reviews and discusses personnel and general management issues before making recommendations to the Board of Trustees. It also has responsibility for reviewing the policies and procedures of Rett UK; the majority are reviewed every three years with the exception of The Safeguarding Children and Vulnerable Adults Policy, The Finance Policy and The Reserves Policy which are reviewed annually. Other policies may be reviewed when a change in legislation or guidance necessitates it.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

7339522 (England and Wales)

Registered Charity number

1137820 (England and Wales)

SCO47369 (Scotland)

Registered office

Victory House
Chobham Street
Luton
Bedfordshire
LU1 3BS

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

Trustees

Ms H Truss
Mr R H Valentine (resigned 8/8/2022)
Mr M Britten
Mr P R Gander
Mr D A Rogerson
Ms C J M Madden (resigned 17/2/2022)
Mr C R Beadle
Mrs J Campobello
Mr S Ledger
Mrs P S Bardon
Mr G Lawson
Mr A Sadek
E J Le-Warde (appointed 30/4/2021)

Independent Examiner

John Thacker FCA DChA
Institute of Chartered Accountants in England and Wales
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Bankers

HSBC
Ballards Lane
Church End
Finchley
London
N3 2BH

Metro Bank plc
One Southampton Row
London
WC1B 5HA

Hampshire Trust Bank plc
PO Box 74003
London
EC2P 2QR

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2022

REFERENCE AND ADMINISTRATIVE DETAILS

Patrons

Yvonne Milne MBE
Ann Clwyd MP
Evelyn Glennie DBE
Gloria Hunniford
Jon Snow
Victoria Murphy

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees (who are also the directors of Rett UK (A company limited by guarantee) for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 7th November 2022 and signed on its behalf by:

Ms H Truss - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
RETT UK
(A COMPANY LIMITED BY GUARANTEE)**

Independent examiner's report to the trustees of Rett UK (A company limited by guarantee) ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31st March 2022.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of Institute of Chartered Accountants in England and Wales which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

John Thacker FCA DChA
Institute of Chartered Accountants in England and Wales
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Date: 8th November 2022

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31ST MARCH 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies	2	271,794	31,518	303,312	297,699
Other trading activities	3	5,516	-	5,516	4,370
Investment income	4	289	-	289	628
Other income		<u>10,641</u>	<u>-</u>	<u>10,641</u>	<u>44,860</u>
Total		<u>288,240</u>	<u>31,518</u>	<u>319,758</u>	<u>347,557</u>
EXPENDITURE ON					
Raising funds		71,935	-	71,935	67,036
Charitable activities					
Charitable activities		<u>207,989</u>	<u>31,518</u>	<u>239,507</u>	<u>211,430</u>
Total		<u>279,924</u>	<u>31,518</u>	<u>311,442</u>	<u>278,466</u>
NET INCOME		8,316	-	8,316	69,091
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>
TOTAL FUNDS CARRIED FORWARD		<u><u>189,581</u></u>	<u><u>7,742</u></u>	<u><u>197,323</u></u>	<u><u>189,007</u></u>

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET
31ST MARCH 2022

	Notes	Unrestricted funds £	Restricted funds £	2022 Total funds £	2021 Total funds £
CURRENT ASSETS					
Debtors	10	11,651	-	11,651	9,074
Cash at bank		<u>264,856</u>	<u>7,742</u>	<u>272,598</u>	<u>231,117</u>
		276,507	7,742	284,249	240,191
CREDITORS					
Amounts falling due within one year	11	(86,926)	-	(86,926)	(51,184)
		<u>189,581</u>	<u>7,742</u>	<u>197,323</u>	<u>189,007</u>
NET CURRENT ASSETS					
		<u>189,581</u>	<u>7,742</u>	<u>197,323</u>	<u>189,007</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>189,581</u>	<u>7,742</u>	<u>197,323</u>	<u>189,007</u>
NET ASSETS					
		<u>189,581</u>	<u>7,742</u>	<u>197,323</u>	<u>189,007</u>
FUNDS					
	13			189,581	181,265
Unrestricted funds				<u>7,742</u>	<u>7,742</u>
Restricted funds					
TOTAL FUNDS					
				<u>197,323</u>	<u>189,007</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st March 2022.

The members have not required the company to obtain an audit of its financial statements for the year ended 31st March 2022 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET - continued
31ST MARCH 2022

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 7th November 2022 and were signed on its behalf by:

Ms H Truss - Trustee

The notes form part of these financial statements

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future, including taking into account any potential impact of the Covid-19 pandemic, and on that basis the charity is considered to be a going concern.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

In 2021/22 a number of significant grants were received towards the end of the financial year which clearly related to activities and expenditure covering the following financial year. The accounting policy is to reflect any income received which clearly relates to future years to be shown as Deferred Income in the Balance Sheet. In 2021/22 a figure of £77,146 has been recorded in Creditors as Deferred Income (20/21 £49,102).

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery	- 25% on cost
Fixtures and fittings	- 25% on cost
Computer equipment	- 25% on cost

The charity does not capitalise fixed assets costing less than £500.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK Corporation Tax purposes. Accordingly the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

1. ACCOUNTING POLICIES - continued

Fund accounting

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals payable under operating leases are charged to the Statement of Financial Activities in the year in which they are payable.

Pensions

The pension cost charge represents the contribution payable by the Charity to the employers' defined contribution pension scheme.

2. DONATIONS AND LEGACIES

	2022	2021
	£	£
Donations	167,340	155,089
Legacies	-	2,000
Grants	<u>135,972</u>	<u>140,610</u>
	<u>303,312</u>	<u>297,699</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

2. DONATIONS AND LEGACIES - continued

Grants received, included in the above, are as follows:

	2022	2021
	£	£
Bartle Family Charitable Trust	1,000	-
BBC Children in Need	31,518	24,057
The Wixamtree Trust	-	5,000
The Edgar Lee Foundation	1,250	-
The Steel Charitable Trust	-	10,000
The Sir James Roll Charitable Trust	-	1,000
Masonic	5,000	5,000
Twyford And District Round Table	-	1,728
Demelza Hospice	18,300	1,700
The February Foundation	5,000	-
The Big Give Xmas Challenge 2020	-	2,124
The National Lottery Community Fund	-	90,001
The Big Give Christmas Challenge 2021	18,756	-
Awards	9,802	-
Hargreaves	6,722	-
Contact a family	6,930	-
Arnold Clark	1,000	-
Edward Gostlin	5,000	-
Abingdon Freewheel	694	-
CAF	<u>25,000</u>	<u>-</u>
	<u>135,972</u>	<u>140,610</u>

3. OTHER TRADING ACTIVITIES

	2022	2021
	£	£
Sales	584	1,151
Unity Lottery and 300 Club	3,366	3,160
Other receipts	<u>1,566</u>	<u>59</u>
	<u>5,516</u>	<u>4,370</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

4. INVESTMENT INCOME

	2022	2021
	£	£
Deposit account interest	<u>289</u>	<u>628</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2022	2021
	£	£
Independent Examiner	<u>2,213</u>	<u>2,172</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31st March 2022 nor for the year ended 31st March 2021.

Trustees' expenses

There were no trustees' expenses paid for the year ended 31st March 2022 nor for the year ended 31st March 2021.

7. STAFF COSTS

	2022	2021
	£	£
Wages and Salaries	156,230	157,682
Social Security	15,454	15,701
Employers' Pension	<u>2,259</u>	<u>2,528</u>
	173,943	175,911
Other Staff Costs	<u>57,294</u>	<u>45,938</u>
	<u>231,237</u>	<u>221,849</u>

The average monthly number of employed personnel during the year was:

	2022	2021
Average number	<u>5</u>	<u>5</u>
On a full time equivalent basis	<u>4</u>	<u>4</u>

There are also self employed personnel equating to a further 1 member on a full time equivalent basis.

Key Management personnel remuneration amounted to £48,471 (2021: £45,885)

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	273,642	24,057	297,699
Other trading activities	4,370	-	4,370
Investment income	628	-	628
Other income	<u>44,860</u>	<u>-</u>	<u>44,860</u>
Total	<u>323,500</u>	<u>24,057</u>	<u>347,557</u>
EXPENDITURE ON			
Raising funds	67,036	-	67,036
Charitable activities			
Charitable activities	<u>187,373</u>	<u>24,057</u>	<u>211,430</u>
Total	<u>254,409</u>	<u>24,057</u>	<u>278,466</u>
NET INCOME	69,091	-	69,091
RECONCILIATION OF FUNDS			
Total funds brought forward	<u>112,174</u>	<u>7,742</u>	<u>119,916</u>
TOTAL FUNDS CARRIED FORWARD	<u>181,265</u>	<u>7,742</u>	<u>189,007</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

9. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1st April 2021	250	2,472	3,824	6,546
Disposals	<u>-</u>	<u>-</u>	<u>(1,641)</u>	<u>(1,641)</u>
At 31st March 2022	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
DEPRECIATION				
At 1st April 2021	250	2,472	3,824	6,546
Eliminated on disposal	<u>-</u>	<u>-</u>	<u>(1,641)</u>	<u>(1,641)</u>
At 31st March 2022	<u>250</u>	<u>2,472</u>	<u>2,183</u>	<u>4,905</u>
NET BOOK VALUE				
At 31st March 2022	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
At 31st March 2021	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022 £	2021 £
Trade debtors	948	-
Prepayments	<u>10,703</u>	<u>9,074</u>
	<u>11,651</u>	<u>9,074</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2022	2021
	£	£
Trade creditors	7,650	-
Other creditors	2,130	2,082
Accruals and deferred income	<u>77,146</u>	<u>49,102</u>
	<u>86,926</u>	<u>51,184</u>

12. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2022	2021
	£	£
Within one year	1,824	17,004
Between one and five years	<u>2,736</u>	<u>4,560</u>
	<u>4,560</u>	<u>21,564</u>

13. MOVEMENT IN FUNDS

	At 1/4/21	Net movement in funds	At 31/3/22
	£	£	£
Unrestricted funds			
General fund	181,265	8,316	189,581
Restricted funds			
Research Fund	7,742	-	7,742
	<u>189,007</u>	<u>8,316</u>	<u>197,323</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2022

13. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	288,240	(279,924)	8,316
Restricted funds			
BBC Children in Need	31,518	(31,518)	-
	<u>319,758</u>	<u>(311,442)</u>	<u>8,316</u>

Comparatives for movement in funds

	At 1/4/20 £	Net movement in funds £	At 31/3/21 £
Unrestricted funds			
General fund	112,174	69,091	181,265
Restricted funds			
Research Fund	7,742	-	7,742
	<u>119,916</u>	<u>69,091</u>	<u>189,007</u>

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	323,500	(254,409)	69,091
Restricted funds			
BBC Children in Need	24,057	(24,057)	-
	<u>347,557</u>	<u>(278,466)</u>	<u>69,091</u>

13. MOVEMENT IN FUNDS - continued

Research Funds

All monies in the Research Funds are utilised to support possible treatments and cures.

14. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31st March 2022.

E J Le-Warde, a Trustee, is the son of a member of staff.

RETT UK

England & Wales - Charity number 1137820

Accounts

REGISTERED COMPANY NUMBER: 7339522 (England and Wales)
REGISTERED CHARITY NUMBER: England and Wales: 1137820, Scotland: SCO47369

REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST MARCH 2021
FOR
RETT UK
(A COMPANY LIMITED BY GUARANTEE)

Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

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FOR THE YEAR ENDED 31ST MARCH 2021

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REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31st March 2021. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

About Rett Syndrome

Imagine being told the toddler you thought was healthy, but perhaps slow to progress, in fact had a rare and devastating disability that would leave them needing lifelong 24/7 care. That is the reality for parents receiving a diagnosis of Rett syndrome for their child. Rett UK is the national charity dedicated to supporting and empowering people with Rett syndrome and their families.

Although present at birth, Rett syndrome is usually undetected until a major regression occurs at around two years of age. Children lose acquired skills and the complexity of the disability is revealed. Rett syndrome is a severe, life long, life limiting genetic neurological disorder; the most common cause of profound disabilities affecting females (1 in 10,000).

Our services empower families, build their emotional resilience, support positive relationships within the family and help reduce isolation improving the health and well-being of all family members including the person with Rett syndrome. When your GP has never heard of it and the paediatrician only recalls reading about it in a text book, the families feel they are in a black hole. Access to high quality information, advice and support is not only vital but life changing.

Our national telephone helpline is the first point of call for desperately worried parents, not just at the point of diagnosis but at moments of crisis; a sudden deterioration in their daughter's health, cuts to respite and care packages, bereavement. We advocate on their behalf especially for education, communication training and therapy services.

Local family led support groups, a parent-to-parent contact network, access to high quality seminars from the UK's leading experts on Rett syndrome at Regional Roadshows and Family Weekends and, more recently, online provides families with up to date, accurate information in subjects like epilepsy, spinal surgery, sleep and breathing, helping them with management of the disability. We also have a dedicated project helping people with Rett syndrome to maximise their communication potential and provide support, training and advice to a UK wide network of speech and language therapists who are working with individual who have Rett syndrome.

Objectives and aims

Our purpose...

Rett UK is a national charity dedicated to supporting and empowering people with Rett syndrome and their families. We are a membership organisation and welcome members from the UK and abroad.

Our strategic aims are to ...

- provide professional family-support services, activities and events at a local, regional and national level
 - educate health, social care and education professionals about Rett syndrome to enable quicker diagnosis and improved standards of care throughout the UK
 - advocate for people with Rett syndrome to be given the support and resources needed to be active communicators
 - promote, support and encourage research into new therapies and treatments for Rett syndrome
- Our vision...

That everyone with Rett syndrome is given every possible opportunity to achieve their individual potential so that they may live their life to the full.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

OBJECTIVES AND ACTIVITIES

Public benefit

In shaping our objectives and planning our activities for the year, the Trustees have given consideration to the duties set out in section 17(5) of the Charities Act 2011 to have due regard to public benefit and to the Charity Commission Guidance on public benefit. In particular, the Trustees have considered how the planned activities will contribute to the overall aims and objectives that they have set.

The Trustees believe that the paragraph, specifically on "Achievements and Performance" for the year, relate in detail the benefit that the charity provides to the public.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

ACHIEVEMENT AND PERFORMANCE

Charitable activities

The financial position at the start of 2020/21 was extremely challenging. It was difficult to see at that point how we would achieve our budget with much of the planned income at risk due to the pandemic. Rett UK launched a successful campaign to raise funds via an emergency appeal to members and the public, as well as securing a sizeable grant from the National Lottery Community Fund. We then managed our costs carefully during the year, made appropriate use of the government's Furlough Scheme and successfully applied for a number of grants. This has left us in a position at the end of the year with a surplus of £69,091 and a cash balance of £231,116 at 31 March 2021 as we head into a second year of Covid challenges. We have achieved this financial position whilst continuing to support families through a difficult year.

COVID-19 response

We continued to respond to the pandemic in a way that would enable us to react quickly and offer the extremely high standard of support that people have come to expect from us. The team really came together and selflessly put in place solutions that were welcomed by our community.

Just some of the things we did:

- Increasing our support line hours to ensure that families had someone to call when needed.
- Transitioning to a remote and online work style while still supporting people using traditional communication methods
- Recording and streaming relevant webinars with expert speakers (available via Rett UK's website)
- Move conferences online and support those with excellent resources

Rebuild Family Life Post Covid-19

To help build resilience, self-esteem and confidence and deal with the challenges families are facing, we launched our Rebuild Family Life Post Covid-19 project. The project was made up of three distinct elements:

- Coaching Sessions - 10 parent carers a course of 8 dedicated sessions with a holistic practitioner that can help coach them through a bespoke support plan, building their resilience, self - esteem and confidence to deal the challenges they are facing.
- Webinars & Workshops - facilitated group sessions to help parent carers build essential skills in challenging & uncertain times; handling uncertainty, reducing anxiety, maintaining resilience, coping with stress, making difficult choices, dealing with change, influencing others, asserting gracefully.
- Rett UK Noodles - A set of short videos that may help with the incredible overwhelm of daily life for those affected by Rett Syndrome.

Maximising the communication potential of people with Rett syndrome

Rett Education 2020 - Communicate, Educate, Advocate.

Due to the ongoing pandemic the conference took a very different form from the original plan but whilst different - and hard work - it was an amazing experience, with a reach far beyond anything we could have envisaged. Moving online allowed us to draw upon a cohort of international (and national) speakers of an incredibly high calibre and attracted families and professionals from across the world as well as the UK.

By the close of the conference a total of 2884 people had registered, signing up to an average of 12 talks per person, and as the majority of talks will continue to be available on replay for 12 months the number of sign-ups is still rising after the close of the conference week - (available via conference website)

During preparation for the conference, we were also delighted to secure sponsorship deals with 5 AAC companies in the UK - 3 we already have a relationship with - Tobi Dynavox, Smartbox and Liberator - and 2 new - Widgit and EyeTech.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

Rett Syndrome Communication Guidelines UK

The UK updated guidelines launched and are designed for parents, carers, therapists and educators. They help by setting a baseline of good practice in developing the communication skills of people with Rett syndrome. They are a starting point for assessment, intervention and long-term management. From this detailed baseline, local and personal practice can be built. The free digital version has been released and print copies will be distributed when printed. We continue to work in recommendations from the Guidelines into all the presentations and training we are developing.

Rett UK Loan Program

The loan programme which we revised in 2020 is a key aspect of Regional Communication Champions work. The programme allows families to use devices and trial various software all with support from the Rett UK communication team.

Feedback from families

All families were very positive about the structured way in which we had managed the loan program and the high level of support they had received throughout. Some of the comments are below:

"We would really like to be able to have a device available to X long term, it is difficult to go back to using only low tech when X was doing so well and seemed really happy using it.

Thank you so much for giving us this opportunity."

"I am so grateful to Rett UK for the experience of the loan device. It has definitely worked for us and we hope to have our own device very soon to continue the hard work we've all been putting in to help communicate with our daughter. "

Discussion groups

We launched monthly discussion groups in February as a follow-on to Rett Education 2020. These have proved fruitful with attendees from the UK, NL and US. The first set of topics were:

- Getting Started with Communication - Susan Norwell
- AAC in Schools - Richard Cloudesley School, Eloise Wright, Callie Ward
- Getting Started with Communication with Adults - Jaqui Mills

Bitesize training and communication resources

We recorded new bitesize training videos to support all those on the communication journey with concise short videos, each being no longer than 15 minutes in length. The first three topics were:

- "What is Communication?"
- "Advocating for Communication"
- "AAC Terminology Explained"

EHCP work

Since procuring some funding for additional project hours to support families with EHCPs, we have spent many hours supporting families with their EHCP documents and Annual Reviews. It is evident that there is a need for this service, and that families are not clear on the purpose of an EHCP, what it entitles them to, what the different timeframes within the process are, and how much authority they wield over finalising the document content.

Online friendship/social groups

The team have developed plans for a pilot group of 6 sessions. Based on responses, we will select the relevant parameters and run the pilot, with possible support from other RCCs.

Regional Communication Champions

Over the year we have stepped up our training programme with our Regional Communication Champions. We now have a training session each month provided by Tobii Dynavox, in addition to the monthly RCC business meetings. In February we have also scheduled a two-hour training session with Smartbox (and before Christmas we had an hour's training session with Widgit). We are also exploring ways to recruit more RCCs and perhaps to recruit student volunteers to support RCCs (from university SLT courses)

Publications/talks/presentations

- A research paper by Callie Ward & Gill Townend was published in the scientific journal Research in Developmental Disabilities. This presents the research into assessment of language and cognition in children with Rett syndrome that they undertook in 2019, with support from Rett UK. It makes a significant contribution to the international debate on this topic and flags up the key role played by Rett UK. It is a free access article and can be downloaded from: <https://doi.org/10.1016/j.ridd.2021.103961>
- We gave a presentation on Rett Syndrome, its genetics, key features and impact on communication to the Scottish Learning Disabilities Clinical Excellence Network in January. This was part of a series of talks with a focus on rare genetic syndromes.
- The communications team recorded a presentation for the Rett UK Online Family Roadshow in March: "Rett UK Communication & Education Support Team: who we are and what we do." At the end of the presentation the first of the bitesize training videos was aired.
- The team also held a live online "Communication Clinic" during the Family Roadshow.

This work continues to make a huge difference to many people with Rett syndrome and has a direct impact on their health and well-being.

Here mum Joanna Tomlin explains why the Rett UK eye gaze loan device is so valuable;

"As for the eye gaze loan that is brilliant! Keisha is enjoying it so much that I am actually surprised. We have incorporated yes and no cards which she now uses fluently. It is so wonderful to witness that little bit of independence that she now has. We are slowly adding other cards (Like, more, stop) to build up our vocabulary.

Our SLT Ruth has come out every Monday and has worked solidly with us for approx 3hrs a time. Ruth has also taught us so much. I'm still waiting to hear from Jenny who is the regional communication champion, but I'm sure she will get in touch soon. I feel as if I'm learning a whole new language.

Keisha can actually make a definitive choice now and can tell me if she is happy/sad, in pain or not. It's been quite emotional and I have shed a tear or two with happiness these last couple of weeks. So thank you it's been incredible!"

Connecting Families and Reducing Isolation

During the year our membership rose again to over 2500 people.

Our TESS service (Telephone Electronic Support Services) delivered by our Family Support team, remains the first port of call for those affected by this devastating disorder with more families making contact especially via social media in the first instance but then signing up to become members and accessing the full range of support services available.

Every quarter we have over 500 individual points of contact with family members but this excludes Facebook responses, What's App, Twitter, Instagram and Facebook messenger which are challenging to be able to capture accurately. These points of contact were through calls to our telephone helpline, via our support email, direct correspondence.

Some of these calls may just be for information about Rett syndrome or a specific symptom, others will be highly charged emotional calls from newly diagnosed families so they vary in intensity and length of call but our family support team members are highly skilled and trained to deal with any call they receive and are able to offer comfort, support, empathy, guidance, advice and information.

Our Regional Roadshows were always hugely popular events with families and the professionals involved in supporting them unfortunately all plans for physical events were postponed due to the pandemic. We were able to use an online platform and put on an Online Family Roadshow. The roadshow had over 30 speakers presenting on a variety of Rett Syndrome related topics. Over the course of the week well over 1000 talks were watched. As with the Rett Education conference the talks from the family roadshow remain up on Rett UK's website to watch again.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

Partnerships, Alliances, Campaigning and Awareness Raising

We continue to work and grow our partnership with Reverse Rett under the RDA banner and ran a joint campaign to encourage people to fill in the survey to help update the Health Checklist. As well as collaborative events we also recorded a joint talk for the Online Regional Day Conference.

Rett UK is also a member of The Helplines Partnership, Genetic Alliance UK, Embracing Complexity, The NVCO, Bedfordshire Chamber of Commerce and takes an active role in The Disabled Children's Partnership Campaign to highlight the challenges faced by families who have children with disabilities.

NHS Clinics

Our specialist Rett clinics which run at 4 locations (Cardiff, Manchester, London and Nottingham) struggled to continue operating throughout this difficult year. The London clinic was the only clinic holding regular appointments all virtually using Microsoft Teams, which is a less than an ideal scenario.

540 people have attended Rett specialist clinics since they started:

- 78 people have attended an adult clinic
- 370 people have attended a paediatric clinic

This is an invaluable service to families who struggle to find someone who has a knowledge of the syndrome locally given the rarity of the disorder. We continue to explore ways to develop these clinics and, in particular, to have something similar for families in Scotland.

Rett UK continues to strive to make a difference to families living with the daily challenges of Rett syndrome; whether that is reducing the isolation they experience, empowering them to be the best advocates they can for their daughter or son, building their emotional resilience, improving their health and well-being and that of the person they care for, helping them maintain positive relationships within the family and ensuring they are able to maximise their family income from the benefits they are entitled to. Rett UK is giving a brighter future to anyone affected by this devastating disorder.

FINANCIAL REVIEW

Principal funding sources

Rett UK is funded by donations from individuals, corporations and trusts. The Board of Trustees reviews the funding to limit the exposure to any particular source of funds.

Where funds are received from donors with a restriction on their use they are held in separate restricted funds.

Investment policy and objectives

The Finance Committee will recommend and monitor the investment structure, risk profile and priorities of the Charity's investments and for this purpose may seek appropriate advice from an independent intermediary / advisor who is authorised by the FCA. Recommendations will be brought to the Board of Trustees at the next meeting. The Finance Committee has delegated powers to authorise any necessary urgent changes, which will be circulated to The Board of Trustees, normally by e-mail, for comment/agreement within 7 days.

Rett UK's investments currently comprise cash held on deposit with Hampshire Trust Bank. This enables easy and speedy access to funds and reflects the Board's low risk approach to investments.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

FINANCIAL REVIEW

Reserves policy

Rett UK has a policy of maintaining a general (or unrestricted) reserve of between 3 and 6 months' running costs, calculated against the current year's budgeted general expenditure. The lower amount is to provide a safe margin for the security of Rett UK's ongoing work. The higher amount is to ensure that funds are consistently disbursed towards the charitable objectives of Rett UK. That range of general reserve also includes an awareness of the likely costs of redundancy payments and other winding up costs should Rett UK decide, or be forced, to cease operations.

Any divergence from holding a general reserve of between 3 and 6 months running costs will be discussed by the Board of Trustees with a clear indication of how and when Rett UK will seek to return to a reserve within its agreed policy range. At the end of the 2021 Financial Year the charity's unrestricted reserves amounted to 6.7 months of budget running costs (against the revised post Covid-19 budget of £321,000 for the financial year 2021-22.) Trustees consider to be prudent in the short term in the light of the ongoing uncertainties caused by the Covid pandemic.

Rett UK will regularly monitor its reserves via the Honorary Treasurer and CEO who will report the current reserve to each quarterly Finance Committee and Trustee meeting.

This policy will be reviewed at least annually by the Finance Committee, normally in the final quarter of each financial year, as part of the budget setting process for the following financial year. The Finance Committee will bring any recommendations or observations to the Board of Trustees at the following meeting.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The organisation is a company limited by guarantee, incorporated on 9 August 2010 and registered as a charity on 6 September 2010.

The company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed by its Articles of Association. Copies of the Articles of Association are available at www.rettuk.org or from its Head Office by request.

The charity was formed to continue the work of Rett Syndrome Association UK (working name RSAUK) a charity registered in 1986, and given a more succinct name.

The members have guaranteed to contribute a maximum of £10 each in the event of the company being wound up.

Organisational structure

The charity is run by a management committee comprising the trustees and co-opted members, who delegate the day to day running to the Chief Executive Officer, Robert Adamek.

Appointment, and Induction and training of new trustees

The Directors are Charity Trustees as defined by section 177 of the Charities Act 2011. Trustees are appointed by ordinary resolution and at each Annual General Meeting one-third of the Trustees must retire, but may be reappointed. The present trustees may appoint new Trustees but those Trustees appointed by the Trustees must retire at the next Annual General Meeting.

Prospective members of the Board of Trustees are given a file of introductory papers including planning and strategic documents and other relevant documentation. They will normally attend at least one Trustee meeting as an observer.

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

STRUCTURE, GOVERNANCE AND MANAGEMENT

Internal Control and Risk management

The Board of Trustees is responsible for the charity's system of internal control and for reviewing its effectiveness. It acknowledges that such a system can only manage and mitigate risk rather than finally eliminate the risk of failure to achieve set objectives. The management of risk is delegated to the CEO who has implemented a risk management policy and provides reports to Trustees at each board meeting. Our systems of control include a three-year Business Plan written by the CEO and an Annual Budget. Regular consideration is given to monitoring the actual performance against the budget and forecasts and to the formal delegation to spend within clearly defined limits.

Having examined the major strategic, business and operational rules which the Charity faces, the Board of Trustees confirms that systems have been established to minimise organisational and financial risks.

The Board of Trustees has established two sub-committees, each with specific terms of reference and chaired by a member of the Board of Trustees.

The Finance Committee, Chaired by the Treasurer, discusses and agrees the annual budget (including approving salary reviews) for approval by the Board of Trustees. It monitors the investment structure, risk profile and priorities of the charity's investments and for this purpose may seek appropriate advice from an independent intermediary / adviser who is authorised by the FCA. It reviews the annual audit plan of the external organisation's Reserves' Policy and practice and makes appropriate recommendations to the Board of Trustees.

The Management Committee reviews and discusses personnel and general management issues before making recommendations to the Board of Trustees. It also has responsibility for reviewing the policies and procedures of Rett UK; the majority are reviewed every three years with the exception of The Safeguarding Children and Vulnerable Adults Policy, The Finance Policy and The Reserves Policy which are reviewed annually. Other policies may be reviewed when a change in legislation or guidance necessitates it.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Company number

7339522 (England and Wales)

Registered Charity number

England and Wales: 1137820

Scotland: SCO47369

Registered office

Victory House
Chobham Street
Luton
Bedfordshire
LU1 3BS

Trustees

Ms H Truss
Mr R H Valentine
Mr M Britten
Mr P R Gander
Mr D A Rogerson
Ms C J M Madden
Mr C R Beadle
Mrs J Campobello
Mr S Ledger
Mrs P S Bardon
Mr G Lawson (appointed 29/9/2020)
Mr A Sadek (appointed 7/10/2020)

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

REFERENCE AND ADMINISTRATIVE DETAILS

Independent Examiner

John Thacker FCA DChA
Institute of Chartered Accountants in England and Wales
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Bankers

HSBC
Ballards Lane
Church End
Finchley
London
N3 2BH

Metro Bank plc
One Southampton Row
London
WC1B 5HA

Hampshire Trust Bank plc
PO Box 74003
London
EC2P 2QR

Patrons

Yvonne Milne MBE
Ann Clwyd MP
Evelyn Glennie DBE
Gloria Hunniford
Jon Snow
Victoria Murphy

STATEMENT OF TRUSTEES' RESPONSIBILITIES

The trustees (who are also the directors of Rett UK (A company limited by guarantee) for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

REPORT OF THE TRUSTEES
FOR THE YEAR ENDED 31ST MARCH 2021

STATEMENT OF TRUSTEES' RESPONSIBILITIES - continued

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Approved by order of the board of trustees on 19 October 2021 and signed on its behalf by:

Ms H Truss - Trustee

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
RETT UK
(A COMPANY LIMITED BY GUARANTEE)

Independent examiner's report to the trustees of Rett UK (A company limited by guarantee) ('the Company')

I report to the charity trustees on my examination of the accounts of the Company for the year ended 31st March 2021.

Responsibilities and basis of report

As the charity's trustees of the Company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

Having satisfied myself that the accounts of the Company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your charity's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5) (b) of the 2011 Act.

Independent examiner's statement

Since your charity's gross income exceeded £250,000 your examiner must be a member of a listed body. I can confirm that I am qualified to undertake the examination because I am a registered member of Institute of Chartered Accountants in England and Wales which is one of the listed bodies.

I have completed my examination. I confirm that no matters have come to my attention in connection with the examination giving me cause to believe:

1. accounting records were not kept in respect of the Company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities (applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

John Thacker FCA DChA
Institute of Chartered Accountants in England and Wales
Chariot House Limited
Chartered Accountants
44 Grand Parade
Brighton
East Sussex
BN2 9QA

Date: 26 October 2021

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

STATEMENT OF FINANCIAL ACTIVITIES
(INCORPORATING AN INCOME AND EXPENDITURE ACCOUNT)
FOR THE YEAR ENDED 31ST MARCH 2021

		Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
INCOME AND ENDOWMENTS FROM	Notes				
Donations and legacies	2	273,642	24,057	297,699	314,007
Other trading activities	3	4,370	-	4,370	6,071
Investment income	4	628	-	628	59
Other income		<u>44,860</u>	<u>-</u>	<u>44,860</u>	<u>-</u>
Total		323,500	24,057	347,557	320,137
EXPENDITURE ON					
Raising funds		67,036	-	67,036	103,805
Charitable activities					
Charitable activities		187,373	24,057	211,430	285,689
		<u>187,373</u>	<u>24,057</u>	<u>211,430</u>	<u>285,689</u>
Total		254,409	24,057	278,466	389,494
		<u>254,409</u>	<u>24,057</u>	<u>278,466</u>	<u>389,494</u>
NET INCOME/(EXPENDITURE)		69,091	-	69,091	(69,357)
		<u>69,091</u>	<u>-</u>	<u>69,091</u>	<u>(69,357)</u>
RECONCILIATION OF FUNDS					
Total funds brought forward		112,174	7,742	119,916	189,273
		<u>112,174</u>	<u>7,742</u>	<u>119,916</u>	<u>189,273</u>
TOTAL FUNDS CARRIED FORWARD		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>

The notes form part of these financial statements

RETT UK
(A COMPANY LIMITED BY GUARANTEE) (REGISTERED NUMBER: 7339522)

BALANCE SHEET
31ST MARCH 2021

	Notes	Unrestricted funds £	Restricted funds £	2021 Total funds £	2020 Total funds £
CURRENT ASSETS					
Debtors	10	9,074	-	9,074	4,108
Cash at bank		<u>223,375</u>	<u>7,742</u>	<u>231,117</u>	<u>122,233</u>
		232,449	7,742	240,191	126,341
CREDITORS					
Amounts falling due within one year	11	(51,184)	-	(51,184)	(6,425)
		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>
NET CURRENT ASSETS					
		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>
TOTAL ASSETS LESS CURRENT LIABILITIES					
		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>
NET ASSETS					
		<u>181,265</u>	<u>7,742</u>	<u>189,007</u>	<u>119,916</u>
FUNDS					
	13				
Unrestricted funds				181,265	112,174
Restricted funds				<u>7,742</u>	<u>7,742</u>
TOTAL FUNDS					
				<u>189,007</u>	<u>119,916</u>

The charitable company is entitled to exemption from audit under Section 477 of the Companies Act 2006 for the year ended 31st March 2021.

The members have not required the company to obtain an audit of its financial statements for the year ended 31st March 2021 in accordance with Section 476 of the Companies Act 2006.

The trustees acknowledge their responsibilities for

- (a) ensuring that the charitable company keeps accounting records that comply with Sections 386 and 387 of the Companies Act 2006 and
- (b) preparing financial statements which give a true and fair view of the state of affairs of the charitable company as at the end of each financial year and of its surplus or deficit for each financial year in accordance with the requirements of Sections 394 and 395 and which otherwise comply with the requirements of the Companies Act 2006 relating to financial statements, so far as applicable to the charitable company.

These financial statements have been prepared in accordance with the provisions applicable to charitable companies subject to the small companies regime.

The financial statements were approved by the Board of Trustees and authorised for issue on 19 October 2021 and were signed on its behalf by:

Ms H Truss - Trustee

The notes form part of these financial statements

NOTES TO THE FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31ST MARCH 2021

1. ACCOUNTING POLICIES

Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention.

At the time of approving the financial statements, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future, including taking into account any potential impact of the Covid-19 pandemic, and on that basis the charity is considered to be a going concern.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

In 2020/21 a number of significant grants were received towards the end of the financial year which clearly related to activities and expenditure covering the following financial year. The accounting policy has therefore been reviewed by the Trustees and changed permanently to reflect any income received which clearly relates to future years to be shown as Deferred Income in the Balance Sheet. In 2020/21 a figure of £49,102 has been recorded in Creditors as Deferred Income.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Tangible fixed assets

Depreciation is provided at the following annual rates in order to write off each asset over its estimated useful life.

Plant and machinery	- 25% on cost
Fixtures and fittings	- 25% on cost
Computer equipment	- 25% on cost

The charity does not capitalise fixed assets costing less than £500.

Taxation

The Charity is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK Corporation Tax purposes. Accordingly the Charity is potentially exempt from taxation in respect of income or capital gains received within categories covered by Chapter 3 Part 11 Corporation Tax Act 2010 or Section 256 of the Taxation of Chargeable Gains Act 1992, to the extent that such income or gains are applied exclusively to charitable purposes.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Designated funds are unrestricted funds of the charity which the trustees have decided at their discretion to set aside to use for a specific purpose

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

1. ACCOUNTING POLICIES - continued

Fund accounting

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals payable under operating leases are charged to the Statement of Financial Activities in the year in which they are payable.

Pensions

The pension cost charge represents the contribution payable by the Charity to the employers' defined contribution pension scheme.

2. DONATIONS AND LEGACIES

	2021	2020
	£	£
Donations	155,089	221,514
Legacies	2,000	12,000
Grants	<u>140,610</u>	<u>80,493</u>
	<u>297,699</u>	<u>314,007</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

2. DONATIONS AND LEGACIES - continued

Grants received, included in the above, are as follows:

	2021	2020
	£	£
Bartle Family Charitable Trust	-	1,000
BBC Children in Need	24,057	13,474
The Wixamtree Trust	5,000	5,000
The Boshier-Hinton Foundation	-	2,000
Other Grants	-	8,875
The Big Give Christmas Challenge 2019	-	22,894
The Edgar Lee Foundation	-	500
The Leathersellers Company Charitable Fund	-	1,000
The Steel Charitable Trust	10,000	12,000
The Souter Charitable Trust	-	2,000
The Woodroffe Benton Foundation	-	1,000
The Thomas Siveright Catto Charitable Settlement	-	750
The Sir James Roll Charitable Trust	1,000	1,000
The Goldsmiths Company	-	3,000
Kents Community Foundation	-	3,000
Army of Us	-	3,000
Masonic	5,000	-
Twyford And District Round Table	1,728	-
Demelza Hospice	1,700	-
The Big Give Xmas Challenge 2020	2,124	-
The National Lottery Community Fund	90,001	-
	<u>140,610</u>	<u>80,493</u>

3. OTHER TRADING ACTIVITIES

	2021	2020
	£	£
Sales	1,151	2,376
Unity Lottery and 300 Club	3,160	3,467
Other receipts	<u>59</u>	<u>228</u>
	<u>4,370</u>	<u>6,071</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

4. INVESTMENT INCOME

	2021	2020
	£	£
Deposit account interest	<u>628</u>	<u>59</u>

5. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2021	2020
	£	£
Independent Examiner	<u>2,172</u>	<u>2,130</u>

6. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31st March 2021 nor for the year ended 31st March 2020.

Trustees' expenses

	2021	2020
	£	£
Trustees' expenses	<u>-</u>	<u>692</u>

Expenses were reimbursements for travel to no (2020: 1) Trustees.

7. STAFF COSTS

	2021	2020
	£	£
Wages and Salaries	157,682	237,949
Social Security	15,701	15,466
Employers' Pension	<u>2,528</u>	<u>2,715</u>
	175,911	256,130
Other Staff Costs	<u>45,938</u>	<u>23,864</u>
	<u>221,849</u>	<u>279,994</u>

The average monthly number of employed personnel during the year was:

	2021	2020
Average number	<u>5</u>	<u>5</u>
On a full time equivalent basis	<u>4</u>	<u>5</u>

There are also self employed personnel equating to a further 3 members on a full time equivalent basis.

Key Management personnel remuneration amounted to £45,885 (2020: £49,499)

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

8. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted funds £	Restricted funds £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	300,533	13,474	314,007
Other trading activities	6,071	-	6,071
Investment income	<u>59</u>	<u>-</u>	<u>59</u>
Total	306,663	13,474	320,137
EXPENDITURE ON			
Raising funds	103,805	-	103,805
Charitable activities			
Charitable activities	272,215	13,474	285,689
Total	<u>376,020</u>	<u>13,474</u>	<u>389,494</u>
NET INCOME/(EXPENDITURE)	(69,357)	-	(69,357)
RECONCILIATION OF FUNDS			
Total funds brought forward	181,531	7,742	189,273
TOTAL FUNDS CARRIED FORWARD	<u>112,174</u>	<u>7,742</u>	<u>119,916</u>

9. TANGIBLE FIXED ASSETS

	Plant and machinery £	Fixtures and fittings £	Computer equipment £	Totals £
COST				
At 1st April 2020 and 31st March 2021	<u>250</u>	<u>2,472</u>	<u>3,824</u>	<u>6,546</u>
DEPRECIATION				
At 1st April 2020 and 31st March 2021	<u>250</u>	<u>2,472</u>	<u>3,824</u>	<u>6,546</u>
NET BOOK VALUE				
At 31st March 2021	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>
At 31st March 2020	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

10. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2021	2020
		£	£
Other debtors		-	82
Prepayments		<u>9,074</u>	<u>4,026</u>
		<u>9,074</u>	<u>4,108</u>
11. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		2021	2020
		£	£
Social security and other taxes		-	3,864
Other creditors		2,082	569
Accruals and deferred income		<u>49,102</u>	<u>1,992</u>
		<u>51,184</u>	<u>6,425</u>
12. LEASING AGREEMENTS			
Minimum lease payments under non-cancellable operating leases fall due as follows:			
		2021	2020
		£	£
Within one year		17,004	15,945
Between one and five years		<u>4,560</u>	<u>19,200</u>
		<u>21,564</u>	<u>35,145</u>
13. MOVEMENT IN FUNDS			
		Net	At
	At 1/4/20	movement	31/3/21
	£	in funds	£
Unrestricted funds		£	
General fund	112,174	69,091	181,265
Restricted funds			
Research Fund	7,742	-	7,742
	<u> </u>	<u> </u>	<u> </u>
TOTAL FUNDS	<u>119,916</u>	<u>69,091</u>	<u>189,007</u>

RETT UK
(A COMPANY LIMITED BY GUARANTEE)

NOTES TO THE FINANCIAL STATEMENTS - continued
FOR THE YEAR ENDED 31ST MARCH 2021

13. MOVEMENT IN FUNDS - continued

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	323,500	(254,409)	69,091
Restricted funds			
BBC Children in Need	24,057	(24,057)	-
	<u>347,557</u>	<u>(278,466)</u>	<u>69,091</u>

Comparatives for movement in funds

	At 1/4/19 £	Net movement in funds £	At 31/3/20 £
Unrestricted funds			
General fund	158,038	(45,864)	112,174
Designated - Regional Fund	1,333	(1,333)	-
Designated - Communication Fund	7,160	(7,160)	-
Designated - TESS Fund	<u>15,000</u>	<u>(15,000)</u>	-
	181,531	(69,357)	112,174
Restricted funds			
Research Fund	<u>7,742</u>	-	7,742
	<u>189,273</u>	<u>(69,357)</u>	<u>119,916</u>

13. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	306,663	(352,527)	(45,864)
Designated - Regional Fund	-	(1,333)	(1,333)
Designated - Communication Fund	-	(7,160)	(7,160)
Designated - TESS Fund	-	(15,000)	(15,000)
	<hr/>	<hr/>	<hr/>
	306,663	(376,020)	(69,357)
Restricted funds			
BBC Children in Need	13,474	(13,474)	-
	<hr/>	<hr/>	<hr/>
TOTAL FUNDS	<u>320,137</u>	<u>(389,494)</u>	<u>(69,357)</u>

Research Funds

All monies in the Research Funds are utilised to support possible treatments and cures.

Regional Day Fund

The Fund is to be used to regional days offering support, guidance and latest information around the country.

TESS

This fund is for telephone & electronic support services including the national telephone helpline, email and social media support. The Henry Smith Charity have supported this work for three years. The Wixamtree Trust is also a regular supporter.

Communications Fund

This fund is supporting our dedicated project to help people with Rett syndrome maximise their communication potential.

Children in Need Fund

The project will provide training for using 'eye gaze' equipment for children with Rett Syndrome. The equipment will improve communication for the children, will reduce the stress and anxiety that they experience and build their self esteem.

14. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31st March 2021.