REPORT OF THE TRUSTEES AND

UNAUDITED FINANCIAL STATEMENTS FOR THE YEAR ENDED 31ST MARCH 2023

FOR

<u>RETT UK</u>
(A COMPANY LIMITED BY GUARANTEE)

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

THURSDAY



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30/11/2023 COMPANIES HOUSE

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CHAIR'S REPORT 2022-23 FOR THE YEAR ENDED 31ST MARCH 2023

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

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).

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

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.

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.

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

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.

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.

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

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.

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 as 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.

A COMPANY LIMITED BY GUARANTEE)

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

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 LUI 3BS

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

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 2 10 Char 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

Shona Wardrop

- 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 90A

Date: 30 10 23

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

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

The notes form part of these financial statements

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

BALANCE SHEET 31ST MARCH 2023

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

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

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

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 226 0 for 2013 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 2022/223 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 Grants	187,016 170,674	167,340 135,972
	357,690	303,312

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

2. DONATIONS AND LEGACIES - continued

3.

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	<u>-</u> ·	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	22,896	-
•	170,674	135,972
OTHER TRADING ACTIVITIES		
	2023	2022
	£	£
Sales	2,328	584
Unity Lottery and 300 Club	4,215	3,366
Other receipts	684	1,566
·		
	7,227	5,516

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

4.	INVESTMENT INCOME	2023	2022
	Deposit account interest	£ 155	£ 289
5.	NET INCOME/(EXPENDITURE)		
	Net income/(expenditure) is stated after charging/(crediting):		
	Independent Examiner	2023 £ 2,285	2022 £ 2,213

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	2,247	2,259
	192,560	173,943
Other Staff Costs	<u>52,962</u>	<u>57,294</u>
	245,522	231,237
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)

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

COMPARATIVES FOR THE STATEMENT OF FINA	ANCIAL ACTIVITIES		
1	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	10,641		10,641
Total	288,240	31,518	319,758
EXPENDITURE ON			
Raising funds	71,935	-	71,935
Charitable activities	•		
Charitable activities			
	207,989	31,518	239,507
Total	279,924	31,518	311,442
NET INCOME	8,316	-	8,316
RECONCILIATION OF FUNDS			
Total funds brought forward	181,265	7,742	189,007
TOTAL FUNDS CARRIED FORWARD	189,581	7,742	197,323

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 let April 2022 and 2 let March 2022				
	At 1st April 2022 and 31st March 2023	250	<u>2,472</u>	2,183	4,905
	DEPRECIATION	•			
	At 1st April 2022 and 31st March 2023	250	2,472	2,183	4,905
	NET BOOK VALUE				
	At 31st March 2023				
	At 31st March 2022	<u> </u>		-	-
10.	DEBTORS: AMOUNTS FALLING DUE WI	THIN ONE YEAR		2023 £	2022 . £
	Trade debtors			~ -	948
	Prepayments			19,322	10,703
				19,322	11,651
	CREDITORS AMOUNTS SALVING DUE	VITUUN OND VD	. D		
11.	CREDITORS: AMOUNTS FALLING DUE	WITHIN ONE YEA	AK	2023	2022
				£	£
	Trade creditors			-	7,650
	Other creditors			2,190	2,130
	Accruals and deferred income			43,345	77,146
				45,535	86,926

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	3:	
	Within one year Between one and five years		2023 £ 1,824 	2022 £ 1,824 2,736 4,560
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	<u>-</u>	7,742
	TOTAL FUNDS	197,323	11,223	208,546
	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	365,072	(353,849)	11,223

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	<u>-</u>	7,742
TOTAL FUNDS	189,007	<u>8,316</u>	197,323
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

319,758

(311,442)

Research Funds

TOTAL FUNDS

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

8,316

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.