

<b>Rett UK Ltd. (Charity 1137820)</b> <b>Minutes of Annual General Meeting</b>	
<b>Date:</b> 23rd September 2023	<b>Venue:</b> On Teams
<b>In attendance:</b> Robert Adamek (RA), Cherie Hunter (CH), Christine Humphrey (Ch.H), Harriet (parent)	
<b>Directors Present:</b> Clive Beadle (CB), Stuart Ledger (SL), Joanna Campobello (JC), David Rogerson (DR) , Elliott Le-Warde (ELW), Philip Gander (PG), Michael Britten (MB), Dee Cowburn (DC), Mary Engel (ME)	
<b>Directors Apologies Received:</b> Pauline Bardon (PB), Debbie Cavaldoro (DC), Romi Löffler	
<b>Item Number</b>	
<b>1.</b>	DR welcomed everyone to the meeting which commenced at 12.30pm. Ch.H is a mum to a young lady with Rett syndrome. CH introduced herself as sibling of a deceased lady with Rett syndrome and she is joining the staff team of Rett UK.
<b>2.</b>	<b>Minutes of 2022 AGM</b> <b>Resolution 1:</b> All present agreed the Minutes of the previous AGM and there were no matters arising. The Minutes were approved as a true record and signed by DR. Nominated by PG. Seconded by ELW. Of those in favour – 12 in person on line, 12 by proxy those against – 0 abstentions – 0.
<b>3.</b>	<p>Honorary Chairs Report – DR</p> <p>It has been a busy year for Rett UK. 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.</p> <p>I would also 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 been relatively straight-forward - indeed literally it has largely been a case of running straight forward on the course that Hilary had very much already set.</p> <p>There have, however, been changes on the Board of Trustees. We have welcomed three new trustees: Debbie Cavaldoro, Dee Cowburn and Mary Engel. Not only do they bring expertise in governance, communications, fund raising 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.</p> <p>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!</p> <p>The family support team of Julie Benson and Donna Tinch have 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, both bringing more People with Rett into the programme and working to enhance the skills of those who have now been using eye-gaze devices and other tools for several years.</p>

	<p>This year we have also been able to invest in our IT systems, databases and the website, using funds from the CAF grant. This isn't the most glamorous of work but 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 <a href="http://www.rettuk.org">www.rettuk.org</a>.</p> <p>Looking forward we have our family weekend in October 24 in the Midlands. We continue to develop our links with Reverse Rett and exploring more ways where the charities can work together. There is growing excitement within the Rett community about breakthrough gene therapy treatments, which offer the tantalising prospect of significant improvements in quality of life for people with Rett syndrome. These advances are to be welcomed and celebrated, although caution must remain the watchword until there is evidence-based research to demonstrate their efficacy and safety. Equally, the more advances that science makes, the more critical will the work of Rett UK 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.</p> <p>No questions for DR. Thanks to DR for his report.</p>
4.	<p>Annual Report 2022/23  <b>Resolution 2:</b> Stuart Ledger, Vice Chair, Treasurer and Chair of the Finance Committee.</p> <p>That Rett UK's independently examined Annual Report and Financial Statements for the year ended 31<sup>st</sup> March 2023 resulted with a surplus of £11,223 and a cash balance of £208,546. Income was £365,072. Reserves are slightly higher than in previous years. This includes deferred income for projects continuing into 22/23 and the Family Weekend of 2024 has a ringfenced amount of £64K.</p> <p>SL recommended that the accounts be received and adopted. These will be available on the website.</p> <p>Nominated by SL. Seconded by CB.</p> <p>Of those in favour – 12 in person, 12 by proxy those against – 0 abstentions – 0.</p>
5.	<p>Appointment of Accountant: SL, Vice Chair, Treasurer and Chair of the Finance Committee -  <b>Resolution 3:</b> That Chariot House Chartered Accountants be appointed Accountants for the ensuing year and that they be paid for their services a sum to be determined by the Rett UK Trustee Board. This amount has not increased in the last three years.</p> <p>Nominated by SL. Seconded by PG.</p> <p>Of those in favour – 12 in person, 12 by proxy those against – 0 abstentions – 0.</p>
6.	<p>Election of Board of Trustees of Rett UK: Our governing document states that one third of Trustees shall stand down each year; they may then stand for re-election by the members of the charity. In addition, any Trustees appointed during the year have to stand down and can stand for election to the board. Voting forms are available to all members. You may vote by proxy if you cannot attend on the day.</p> <p><b>New Trustees</b> – DC, DCo standing for election. (Mary Engel and Romi Löffler will be standing at next year's AGM as they joined post Mar 2023)</p> <p>Three current Trustees seeking re-election:  ELW, PB, SL</p> <p>Of those in favour – 12 in person, 12 by proxy those against – 0 abstentions – 0</p>
300 Club	<p><b>400 Club:</b> RETT UK 400 CLUB REPORT TO AGM – 23.09.2023</p> <p>I started a "200 Club" in 1996 to hold monthly prize draws and at the same time to raise funds for the Association. In 2008 we grew into a "300 Club" and in 2023 we became a "400 Club". Since 1996 prize monies of £30,900 have been won and the total raised for Rett UK is over £45,200. Shares still cost £10 each but members may now purchase up to 20 shares. With 392 shares sold this year we very nearly reached our full complement of 400! In 2023 prizes totalling £1,785 will have been won and at least £2,500 raised for Rett UK (which includes some prize monies generously re-donated). Thank you to everyone for their support.</p>

	<p>Many thanks to Donna Tinch for her support with admin from the office.</p> <p>Yvonne Oliver 300 Club Secretary</p> <p>Hilary Truss and Robert Adamek thanked Peter and Yvonne for their continued support with the 400 Club.</p>
<b>AOB</b>	DR asked if there was any other business or any questions – none.
	DR thanked everyone for their attendance and closed the meeting at 1pm.