Rett UK Ltd. (Charity 1137820) Minutes of Annual General Meeting

Date: 28th September 2024 **Venue:** On Teams

In attendance: Robert Adamek (RA), Tom Gander (TG), Hilary Truss (HT)

Directors Present: Stuart Ledger - Treasurer (SL), David Rogerson - Chair (DR), Elliott Le-Warde (ELW), Philip Gander

(PG), Michael Britten (MB), Pauline Bardon (PB),

Directors Apologies Received: Debbie Cavaldoro (DC), Joanna Campobello (JC), Mary Engel (ME), Dee Cowburn (DC),

Clive Beadle (CB)

Item Number

1. DR welcomed everyone to the meeting which commenced at 12.30pm.

2. Minutes of 2023 AGM

Resolution 1: 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 MB.

Of those in favour – 9 in person on line, 6 by proxy those against – 0 abstentions – 0.

3. Honorary Chairs Report – DR

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 Coventry 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, although extreme, 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!

No questions for DR. Thanks to DR for his report.

RA said thanks for his kind words for him and the team, it is very much appreciated.

4. Annual Report 2023/24

Resolution 2: Stuart Ledger, Vice Chair, Treasurer and Chair of the Finance Committee.

That Rett UK's independently examined Annual Report and Financial Statements for the year ended 31st March 2024 resulted with a deficit of £11,679 and a cash balance of £196,167. Income was £306881. Expenditure £318,560 Reserves are slightly higher than in previous years due to planned funding of the 2024 Family Weekend.

SL recommended that the accounts be received and adopted with the only outstanding change is to update the description of Rett syndrome. These will be available on the website.

Nominated by SL. Seconded by MB.

Of those in favour -9 in person, 6 by proxy those against -0 abstentions -0.

5. Appointment of Accountant: SL, Vice Chair, Treasurer and Chair of the Finance Committee -

Resolution 3: 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.

Nominated by SL. Seconded by PB.

Of those in favour -9 in person, 6 by proxy those against -0 abstentions -0.

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.

New Trustees – Mary Engel (ME) and Romi Loffler (RL) have both been active members of the board during the year having been coopted by trustees but need to be formally elected now. DR asked all those in favour to raise their hands. Of those in favour – 9 in person, 6 by proxy those against – 0 abstentions – 0

Tom Gander (TG) also joined us today as a new trustee – DR asked again for votes - Of those in favour -9 in person, 6 by proxy those against -0 abstentions -0

Three current Trustees seeking re-election:

PG, DR JC - DR asked all present to vote individually for the three candidates standing for re-election. Of those in favour - 9 in person, 6 by proxy those against - 0 abstentions - 0

DR thanked trustees for being willing to serve another year and he looks forward to another productive year for Rett UK working with everyone.

300 Club

400 Club: The "200 Club" was established by Yvonne Oliver in 1996 to hold monthly prize draws and at the same time to raise funds for the Association. In 2008 it became a "300 Club" and more recently in 2023 the 400 club. Shares cost £12 each, up to 20 shares per person. This year we sold 3037 shares with prizes just under £2000. This raised £2399 for Rett UK including prize money donated back, around 40% currently.

Many thanks to Donna Tinch for her support with admin from the office. (winners need to be added here from the last draws)

Robert Adamek thanked Yvonne for their continued support with the 300 Club. DR suggested we send a thank you letter to Yvonne Oliver.

AOB

DR asked if there was any other business or any questions – none received in advance. HT said how delighted she was we were having a Family Weekend in October, especially that it is free.

DR thanked everyone for their attendance and closed the meeting at 1pm.