

Zellweger UK – Annual Report and Unaudited Financial Statement.

Constitution Incorporated Organisation registration number: 1166389

1st September 2023 to 31st August 2024

Trustees - Chair – Mrs Natasha Anderson Hunt.

Vice Chair and Head of Safeguarding– Mrs Alexandra McConville

Treasurer – Miss Kerry Hughes

Secretary and Web Design – Ms Carly Brown

Family Liaison – Mrs Rudi Evans

Members -

Family Members supported - 72

Fundraisers – Mark Stoodley from Club Dubs of Vanarchy, George Shurley, Tegan Foxley, Andover College, Gabriel Constant, Rudi Evans, Aldershot LFR, Regitze Lybecker, Abhi stores Ltd and Kerry Hughes.

Number of Volunteers – Fundraising Coordinator – Regitze Lybecker

Bereavement Coordinator – Gillian Donald

General running of Charity - Trustees = 5

Registered Address - 7 Wildmoor Walk, Havant, Hants PO9 5QY.

Correspondence Address - 75 Elder Close, Chard, Somerset, TA20 1BQ

Objects - A. To promote and protect the physical and mental health of sufferers of Peroxisomal Biogenesis Disorder and their families in the U.K. and Ireland by provision of grants and/or equipment, support and practical advice.

B. To advance the education of the public by supporting research into Peroxisomal Biogenesis Disorder and disseminating the useful results for public benefit.

Activities - Zellweger UK has made the decision to hold the Annual Family Conference every two years instead of annually due to rising costs from the Hotel and fall in annual donations. The 2024 Conference has been booked for 2025.

The charity has given out £1468.99 in grants to assist families towards equipment for their children to help with quality of life, such as a baby monitor, posture support pack and 2 wheelchairs. The charity also granted £555.05 towards memory jewellery for parents who are bereaved.

We continue to offer £250 towards memory jewellery for bereaved families, £300 for hospital stay and a £500 per year towards equipment not covered by the NHS for affected children.

The charity continues to run several 24/7 online support groups.

Locations - Zellweger UK is run from England, Devon, Somerset, Wiltshire, Surrey and Hampshire.

Restricted Income – There is currently no restricted income.

Reserves - Zellweger UK has no payroll or assets to maintain. Over heads are minimal allowing profits gained to go direct towards the objects of the charity.

At the end of August 2024 we held £50,076.70 in our accounts, £10,302 of this is reserved in

a fixed 12 months, no access, saving account with 3% interest.
We will review increasing this amount to £20,000 next year.

Values

Zellweger UK is run on an entirely voluntary basis, and we aim to be environmentally conscious in our choices for promotional merchandise and products, using recycled or recyclable materials whenever we can. We have a strict moral code of acceptance and non-judgement, which we promote in our forums and exercise ourselves to try to make a positive difference in peoples' lives.

Fundamental tasks

Our online support forums are available 24 hours a day, 7 days a week for all UK families affected by ZSD/PD. We offer practical assistance and support, facilitate emergency grants, and provide information for families in need of help.

Supporters and collaborators

We continue to be globally partnered with The GFPD (Global Foundation for Peroxisomal Disorders) and to work closely with SENSE, a charity for deafblind people and people with multisensory loss. We also continue to liaise and collaborate with the paediatric metabolic team in Bristol, with consultants and researchers at the AMC (Faculty of Medicine – University of Amsterdam) who collectively made contributions towards our care booklet, and also with Shrader Lab, a team of researchers at the University of Exeter with outreach collaborations.

The Charity made a profit this year of £89.06. There were some conference expenses that came from the previous financial year.

The accounts for the year are as follows, Profit and loss and Balance Sheet.

	Sep '23 - Aug 24
Ordinary Income/Expense	
Income	
Bank Interest Earned	302.00
Club Fundraising	
Club Dubs of Vanarchy	500.00
Total Club Fundraising	500.00
 Easyfundraising	 122.01
Facebook campaigns	
Birthday Donation	25.00
Facebook campaigns - Other	285.00
Total Facebook campaigns	310.00
 Fund Raising Events	
Jingle Bells Rock	315.00
Marathons	510.00
Total Fund Raising Events	825.00
 Gifts and Donations Income	
Gift Aid	154.99
Gifts and Donations Income - Other	784.13

Total Gifts and Donations Income	939.12
In Memory	1,233.75
Investment Income	0.00
King of the tin	435.73
Paypal Giving Fund Uk	198.45
Website Donations	<u>133.00</u>
Total Income	<u>4,999.06</u>
Gross Profit	4,999.06
Expense	
Awards and Grants	
Grants towards Equipment	<u>1,468.99</u>
Total Awards and Grants	1,468.99
Bank Charges	
Just Giving Charges	251.56
PayPal Charges	<u>4.32</u>
Total Bank Charges	255.88
Computer and Internet Expenses	238.66
Conference Expenses	
Childrens entertainment	13.39
Conference Banner	91.24
Leaflets & Flyers	116.16
Conference Expenses - Other	<u>88.56</u>
Total Conference Expenses	309.35
In memory Jewellery	555.05
Office Expense	
Software	1,321.77
Stationery	<u>8.95</u>
Total Office Expense	1,330.72
Postage and Delivery	6.00
Professional Fees	
Bookkeeping	<u>327.50</u>
Total Professional Fees	327.50
Promotional Stock	
T-shirts for fundraisers	<u>320.65</u>
Total Promotional Stock	320.65
Travel and Meetings	

Conference, Meetings	<u>97.20</u>
Total Travel and Meetings	<u>97.20</u>
 Total Expense	 <u>4,910.00</u>
 Net Ordinary Income	 <u>89.06</u>
 Profit for the Year	 <u><u>89.06</u></u>

	<u>31 Aug 24</u>
ASSETS	
Fixed Assets	
Computer Equipment	1,102.94
Furniture and Fixtures	
Medical Equipment	<u>1,944.00</u>
Total Furniture and Fixtures	<u>1,944.00</u>
 Total Fixed Assets	 3,046.94
 Current Assets	
Other Current Assets	
Stock	<u>3,174.90</u>
Total Other Current Assets	3,174.90
 Cash at bank and in hand	
Lloyds Fixed Term Deposit	10,302.00
PayPal	903.82
Zellweger UK	<u>38,870.88</u>
Total Cash at bank and in hand	<u>50,076.70</u>
 Total Current Assets	 53,251.60
 NET CURRENT ASSETS	 <u>53,251.60</u>
 TOTAL ASSETS LESS CURRENT LIABILITIES	 <u>56,298.54</u>
NET ASSETS	<u><u>56,298.54</u></u>
 Capital and Reserves	
Merchandise	2,280.96
Unrestricted Net Assets	53,928.52
Profit for the Year	<u>89.06</u>
Shareholder funds	<u><u>56,298.54</u></u>

Signed Treasurer

A handwritten signature in black ink, appearing to be 'K. Ambler', written over a horizontal line.

Zellweger UK - Annual Chairperson Report

For the period 1st September 2023 – 31 August 2024

2024 has been a difficult year for our charity with the cost of living making its presence felt on our small charity. That said, the positivity continues in the emotional and financial support we have continued to offer families impacted by peroxisomal disorders.

Organisation of our 2025 Family conference and meet is in full swing, and we are looking forward to bringing families together again for a weekend of connections and activities for families affected by Zellweger Spectrum Disorder and other closely related peroxisomal disorders.

A highlight of this year was being invited to offer another presentation on behalf of Zellweger UK, for 3rd year cell biology students at the University of Exeter, this time bringing along a couple of members of my family. It was again received really well from some of the most engaging and inspirational young people I have met. It's always inspiring to stand in front of the next generation of potential researchers.

Moving forward this year we are planning to increase our grant applications to bring some much-needed funds for our upcoming conferences, and to settle a date for the 2027 conference early as well as secure speakers with plenty of advance notice in hope of making the next conference bigger and better than ever.

Signed Chair

A handwritten signature in black ink, appearing to be 'W. Ambler', written in a cursive style.