

Zellweger UK – Annual Report and Unaudited Financial Statement.

Constitution Incorporated Organisation registration number: 1166389

1st September 2022 to 31st August 2023

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 – Jacob Price, Regitze Lybecker, Rudi Evans, Mark Stoodley from Club Dubs of Vanarchy, George Shurley, Jo Bunyan, Sarah Richards, Kingsbridge Risk, Elaine Lainey, Mrs Buckland, Hartpury University, Abhi stores Ltd, Carly Brown, Capital Finance and Leasing Ltd, Michael Scrader Uni of Exeter 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 was really pleased to be able to hold the Annual Family Conference weekend in Devon from the 21st July 2023 to 24th July 2023 after taking several years break due to the risks of COVID. Sixteen families attended along with Scientists from Michael Schraders lab at The University of Exeter, sensory experts from the charity SENSE, children entertainers, face painters, music therapy, etc.

The charity has given out £2281.55 in grants to assist families towards equipment for their children to help with quality of life and the new hospital stay grant.

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 online support groups.

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

Restricted Income - Grants had been received from SSIEM (Society for the Study of Inborn Errors in Metabolism) of £2616.66, Maximus Foundation of £2500 in previous account years and carried forward, a further £2840 last year from Jeans for Genes which was spent on the July 2023 Conference, restricted total to £7956.66. A private donation of £20 was also added

to the event costs. This was an incredible help to cover approximately half the costs of the event.

Confirmation that the grant money was used on the Conference with a break down of the weekend events with gratitude was sent to each grant provider.

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 2023 we held £50,094.43 in our accounts, £10,000 of this is reserved in a fixed 12 months, no access, saving account with 3% interest.

We will review increasing this amount to £15,000 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 Shcrader Lab, a team of researchers at the University of Exeter with outreach collaborations.

Accounts – Profit and loss

	Sep '22 - Aug 23
Ordinary Income/Expense	
Income	
Amazon Smile	120.80
Birthday Donations	110.00
Club Fundraising	
Club Dubs of Vanarchy	2,754.89
Total Club Fundraising	2,754.89
Cycling Fundraising	
Jacob Price	3,587.81
Total Cycling Fundraising	3,587.81
Easyfundraising	78.22
Facebook campaigns	891.03
Fund Raising Events	
Golf	250.00
Marathons	1,230.67
Total Fund Raising Events	1,480.67

Gifts and Donations Income**Gift Aid**

Gift Aid - Repayment Interest 5.20

Gift Aid - Other 1,190.55

Total Gift Aid 1,195.75

Restricted

Family Weekend 20.00

Total Restricted 20.00

Gifts and Donations Income - Other 1,286.90

Total Gifts and Donations Income 2,502.65

In Memory 2,175.00

King of the tin 848.14

Merchandise sold

Bag Sales 0.00

Mugs 6.00

Pens 0.00

Sports Bottle 0.00

Stress balls 0.00

Trolley coin 3.00

Wrist Bands 0.00

Total Merchandise sold 9.00

Miscellaneous Income 17.98

Paypal Giving Fund Uk 2.50

Raffle income 529.00

Website Donations 762.25

Total Income 15,869.94

Cost of Goods Sold

Cost of Goods Sold 398.20

Total COGS 398.20

Gross Profit 15,471.74

Expense**Awards and Grants**

Grants towards Equipment 1,073.94

Gym membership 441.02

Hospital Stay Assistance 600.00

Specific Assist to Individuals

Music Therapy 166.59

Total Specific Assist to Individuals 166.59

Total Awards and Grants	2,281.55
Bank Charges	
Just Giving Charges	221.85
PayPal Charges	13.85
SumUp Card Fees	4.62
Bank Charges - Other	0.00
Total Bank Charges	240.32
Computer and Internet Expenses	697.15
Conference Expenses	
Childrens entertainment	943.35
Kraft Tags	5.53
Neck Wallets Lanyards	170.33
Refreshments	9.98
Tshirts	1,054.87
Total Conference Expenses	2,184.06
Fudraising Equipment	58.80
Insurance Expense	236.60
Office Expense	
Consumables	127.96
Software	1,238.04
Stationery	2.25
Total Office Expense	1,368.25
Postage and Delivery	9.20
Professional Fees	
Bookkeeping	307.50
Total Professional Fees	307.50
Raffle Prizes	46.09
Travel and Meetings	
Conference, Meetings	263.52
Family Day Hotel	11,101.25
Volunteer Mileage	219.06
Volunteer travel	359.24
Total Travel and Meetings	11,943.07
Volunteer Expenses	75.00
Total Expense	19,447.59
Net Ordinary Income	-3,975.85
Profit for the Year	-3,975.85

Amazon Smile have notified us that they will be stopping the donations to Charity.

The Charity made a loss this financial year due to donations being down and grants being given in previous years towards the Conference expenses and then delay in being able to hold the conference due to COVID. The Conference hotel invoice was settled in full this financial year, covered by previous year's profit.

Balance Sheet –

	31 Aug 23
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	10,000.00
PayPal	0
Petty Cash	1,238.54
Zellweger UK	500.00
	38,355.80
	<u>9</u>
Total Cash at bank and in hand	<u>50,094.40</u>
 Total Current Assets	 53,269.30
 Current Liabilities	
Accounts Payable	
Accounts Payable	<u>106.79</u>
Total Accounts Payable	<u>106.79</u>
 Total Current Liabilities	 106.79
 NET CURRENT ASSETS	 53,162.50
 TOTAL ASSETS LESS CURRENT LIABILITIES	 <u>8</u>
 NET ASSETS	 <u>56,209.40</u>
	<u>8</u>

Capital and Reserves

Merchandise	3,174.90
	57,010.4
Unrestricted Net Assets	3
Profit for the Year	-3,975.85
	<u>56,209.4</u>
Shareholder funds	<u>8</u>

Signed Treasurer

**Zellweger UK - Annual Chairperson Report**

For the period 1st September 2022 – 31 August 2023

2023 was a particularly emotionally lifting year for Zellweger UK, with the return of our annual Family Conference, once again held at the Manor House Hotel in Oakhampton; a well overdue emotional but wonderful time for the families we support, for us as a team and everyone involved. We had some incredible speakers, both medical and from the field of Peroxisomal Disorder research. This year our focus was heavily on allowing families time to spend time together, on therapies for children with the wonderful support of the deafblind charity Sense, and on peer-to-peer support, tackling head on some of the hardest impacts of peroxisomal disorder on children and their families.

Moving forward with this, we are aiming to hold our conference biennially, which will allow us more time to finance each conference as well as extra organisational time. With this in mind, we are aiming to open the presentations to healthcare professionals and the members of the teams who support children affected by a peroxisomal disorder.

The efforts of our fundraisers continue to astound me, with the most incredible show of support despite the cost-of-living crisis and such turbulent times. While our finances appear to run at a loss this year due to the cost of our annual conference, funds were already set aside for this and the funds we've raised this year will continue to allow us to support families both emotionally and practically with equipment grants and small financial grants to help cover the increasing cost of multiple/prolonged hospital stays. It will also allow us to continue to support bereaved families with small grants for memorabilia – often in the form of, but not limited to hand/foot/fingerprint jewellery, something that has continued to offer comfort to families who have lost children to this awful disease.

I was grateful to have been invited back by Professor. Michael Schrader, to offer a presentation to undergraduate students as part of a patient-centred session on Cell Biology of Disease at the University of Exeter. I was particularly moved by a student who sent some

incredibly kind and thoughtful feedback that highlights the impact of reaching out to tell the unique and incredible stories of our children.

I hope moving forward that we can continue to increase our outreach and public benefit, especially moving forward with our care booklet for families and healthcare teams of children affected by peroxisomal disorders, which was forced to be put on the backburner in previous years. We will continue to offer support to 72 families and to offer a place of comfort to newcoming families over the next year, to increase public awareness and to support some exciting upcoming research. Here is to an even better 2024.

Signed Chair

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