

Zellweger UK - Annual Report and unaudited financial statement.

Constitution Incorporated Organisation registration number: 1166389

1st September 2020 to 31st August 2021

Trustees - Chair - Mrs Natasha Anderson Hunt.

Vice Chair and Head of Safeguarding- Mrs Alexandra Ley

Treasurer - Miss Kerry Hughes

Web Design - Ms Carly Brown

Fundraising Co-ordinator - Mrs Stephanie Curry

Family Liaison - Mrs Rudi Evans

Members -

Fundraisers - One Stop, Rachel Lund, Regitze Lybecker, Sean McArdel, Mark Stoodley, Rudi Evans, Abhi Stores Ltd (Premier Shop), Judith McGregor, Stephanie Curry, Kerry Hughes, Harry Senior and KCL Neurosurgery Society, Genesis Capital Finance and Leasing Ltd, Alexandra Ley and Blackshaw Primary School.

Photographers - Mr Simon Hawkins, Mr Steve Hughes, Mr Jonathan Warner.

Family Members supported - 66 families

Number of Volunteers -

Volunteers = 5

General running of Charity - Trustees = 6

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 cancelled the annual family Conference in Devon for affected families with Specialist doctors and Scientists due to the risks of COVID 19. Several online sessions are planned to take it place so families can still connect from the safety of their homes. Social media platforms are used to enable Zellweger UK to keep people up to date with activities and news. Bookings are taken for The Conference weekend in July 2022, this will be reviewed again in the New Year regarding the safeguarding of getting together in person.

The charity has given out teddy bears for all the affected children over Christmas which also marks the anniversary for the memory of gorgeous baby Teddy who sadly passed away on Christmas Day the year previous.

The charity has offered a temporary one-off grant of a payment of £300 for any family with affected Children, that are financially struggling due to COVID. This will be reviewed in the New Year. We continue to offer £250 towards memory jewellery for bereaved families and a £500 per year towards equipment not covered by the NHS for affected children.

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

Restricted Income - A grant had been received from SSIEM (Society for the Study of Inborn Errors in Metabolism) of £2616.66 towards our next Conference which is being carried forward into 2022 due to Covid 19 restrictions. We also received a grant from Maximus Foundation of £2500 in this financial year towards the same Conference making the total restricted £5116.66. A report will be sent to both groups after the event so they can see how the money is spent.

Reserves - Zellweger UK has paid a deposit of £4608.75 to the hotel for our Conference before COVID 19 hit, the remaining bill for the 2020 conference was £14,111.25. This had to be cancelled so we have asked the hotel to hold the deposit and book us in for 2022. This is going to be reviewed in January 2022 due to COVID 19. 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 2021 we held £40,184.54 in our accounts, £5000 of this is reserved. We plan to look at opening a second bank account hopefully with interest so we can transfer the reserves of £5000 into this account. We will review increasing this amount at the same time as the charity has grown.

Zellweger UK - Annual Chairperson Report

For the period 1st September 2020 - 31 August 2021

7th February 2022

As we settle into our 7th year running as a charity, I look back on our last running year proud of our team who have not only had the pandemic to deal with, but as parents and bereaved parents of affected children ourselves, have had to cope with various personal struggles during such a difficult time.

Our charity was set up to raise awareness of Zellweger Spectrum Disorder (ZSD), D Bifunctional Protein Deficiency (DBPD), Acyl-CoA Oxidase 1 (ACOX1) and closely related peroxisomal disorders, and to support research into these little-known diseases and the families impacted by them.

I am pleased to say that despite an expected reduction in fundraising, we have continued to successfully focus on sustaining our core services.

Impact

We have continued to offer support to 66 families impacted by ZSD, DBPD and ACOX1.

Sadly, due to the fact that children affected by diseases like ZSD can be so medically fragile, our usual annual family conferences have been paused until we can be sure that we will not be putting families at risk. Therefore, we were forced to cancel our 2021 conference and families were once again unable to meet up in person. However, we have continued to provide online support via our group forums, as well as one to one moral and emotional support.

Public benefit

We have provided a safe space as well as information and support for newly diagnosed families. We have also been able to provide memory jewellery for some of our bereaved families and to prepare an equipment grant and a financial assistance grant for two of our newer families.

We have started to put together our care booklet as a resource for families. Two entries have been approved by both international and UK medical professionals with advanced knowledge on ZSD/PD, with further entries being worked on currently. In continuing our outreach, our annual patient centred presentation for Professor Schrader's 3rd year cell biology students at The University of Exeter, held via Zoom and was another success despite the restrictions of online presenting.

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.

Strategic Objectives

We aim to continue to improve the collection, quality of management and use of data. We would also like to improve our connection with the NHS to collaborate with more healthcare professions and reach as many potential affected families as possible.

We aim to continue creating our care booklet and would like to have a comprehensive list of care advice for patients affected by ZSD/PD completed to a degree that it can be released within the next year.

We will review our current reserves and aim to increase this to cover more accurately running costs.

Risk management

Our safeguarding official has been facilitating trustee DBS checks and is ready to ensure all trustees, volunteers and carers that attend our next conference have up to date DBS checks. She is also ensuring that all health and safety measure are adhered to. We are collaborating to carefully assess the science alongside government guidelines to assess how soon we will return to public meets at our annual conferences.

We only store personal information and photographs with written permission, and we have recently implemented a move over to a more reliable and secure system for safer data storage.

We are planning a change of bank account to better secure our funds.

Fundraising

Despite the ongoing strain of the pandemic, we have received an amazing amount of support from families, fundraisers and grant providers, with The Maximus Foundation providing us with a £2500 grant, Dubs of Vanarchy with their ongoing support raising £1,166.98 for this financial year alone, marathon participants raising £1663.87 collectively and an incredible £4,287 raised by the Workout Challenge created by one of our families as well as many donations from families, friends and extended families. We are so grateful for the ongoing support from so many.

Supporters and collaborators

We will soon be working with Free Wills to encourage legacy giving, which we hope will generate more funds for the charity. 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.

Finances

With a profit of £16,829, we have seen a significant drop in funds compared to previous years. However, given the current financial climate and general pandemic fatigue and burnout so many are feeling, this is an incredible result, and we are extremely proud of and grateful to all of our supporters. We look forward to what the next year brings for our charity and for the families we support.



Natasha Anderson-Hunt: Chairperson – Zellweger UK

Accounts - Zellweger UK Accounts include, Profit and Loss Account for Year Ending August 2021 and Balance Sheet for Year Ending August 2021.

	Sep '20 - Aug 21
Ordinary Income/Expense	
Income	
Amazon Smile	89.26
CAF Charities Aid Foundation	55.00
Club Fundraising	
Club Dubs of Vanarchy	1,166.98
Total Club Fundraising	1,166.98
Easyfundraising	79.41
Facebook campaigns	
Birthday Donation	805.41
Facebook campaigns - Other	2,709.69
Total Facebook campaigns	3,515.10
Fiver for our Fifth	310.45
Fund Raising Events	
Making Bespoke Christmas Decs	357.00
Marathons	1,663.87
My Prudential Ride London	185.00
Skydive	15.00
Workout Challenge	4,286.95
Total Fund Raising Events	6,507.82
Gifts and Donations Income	
Gift Aid donations	516.88
Gifts and Donations Income - Other	1,383.78
Total Gifts and Donations Income	1,900.66

Gifts In Kind	100.00
Giving Tuesday	20.00
Grants - RESTRICTED INCOME	
Maximus Foundation	<u>2,500.00</u>
Total Grants - RESTRICTED INCOME	2,500.00
In Memory	1,992.48
KCL Neurosurgery Society	255.68
King of the tin	817.16
Merchandise sold	
Bag Sales	0.00
Christmas Cards	11.00
Face Masks	458.00
Fans	0.00
Mugs	45.00
Pens	12.50
Sports Bottle	0.00
Stress balls	2.50
Trolley coin	<u>3.50</u>
Total Merchandise sold	532.50
Paypal Giving Fund Uk	
Ebay sales	3.00
Paypal Giving Fund Uk - Other	<u>4.74</u>
Total Paypal Giving Fund Uk	7.74
Postage and Packaging	5.20
Website Donations	<u>192.60</u>
Total Income	20,048.04
Cost of Goods Sold	
Cost of Goods Sold	<u>697.48</u>
Total COGS	<u>697.48</u>
Gross Profit	19,350.56
Expense	
Bank Charges	
PayPal Charges	90.96
Virgin card fee	4.83
Virgin Card Fees	<u>25.38</u>
Total Bank Charges	121.17

Computer and Internet Expenses	232.66
DBS- DISCLOSURE AND BAR	46.00
In memory Jewellery	340.99
Insurance Expense	212.80
Miscellaneous Expense	0.00
Office Expense	
Consumables	131.09
Software	980.09
Stationery	35.13
Supplies	30.00
Total Office Expense	<u>1,176.31</u>
Postage and Delivery	264.11
Teddys for Christmas	111.84
Travel and Meetings	
Travel	<u>15.60</u>
Total Travel and Meetings	15.60
Unauthorised Automated DDs	<u>0.00</u>
Total Expense	<u>2,521.48</u>

Net Ordinary Income 16,829.08

Profit for the Year **16,829.08**

BALANCE SHEET AS AT 31st AUGUST 2021

**31 Aug
21**

ASSETS

Other Assets

Other Assets	<u>150.00</u>
Total Other Assets	150.00

Current Assets

Other Current Assets

	3,644.84
Stock	<u>4</u>
Total Other Current Assets	3,644.84

Cash at bank and in hand

	3,319.97
PayPal	7
Petty Cash	10.00
	36,854.57
Zellweger UK	<u>57</u>
Total Cash at bank	<u>40,184.</u>

and in hand	<u>54</u>
	43,829.
Total Current Assets	38
Current Liabilities	
Accounts Payable	
	14,111.
Accounts Payable	<u>25</u>
Total Accounts Payable	14,111.
	<u>25</u>
	14,111.
Total Current Liabilities	25
	29,718.
NET CURRENT ASSETS	<u>13</u>
TOTAL ASSETS LESS	29,868.
CURRENT LIABILITIES	<u>13</u>
	29,868
NET ASSETS	<u>.13</u>
Capital and Reserves	
	2,280.9
Merchandise	6
	10,758.
Unrestricted Net Assets	09
	16,829.
Profit for the Year	<u>08</u>
	29,868
Shareholder funds	<u>.13</u>

Signed: Miss Kerry Hughes - Treasurer



Signed: Mrs N Anderson-Hunt - Chairperson

