

## **Zellweger UK - Annual Report and unaudited financial statement.**

**Constitution Incorporated Organisation registration number: 1166389**

**1<sup>st</sup> September 2021 to 31<sup>st</sup> August 2022**

**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** - 77 families

**Fundraisers** - Silvie's Café, Community Academy Birchwood Primary School, Mark Stoodley from Club Dubs of Vanarchy, Blackshaw Primary School, Alex McConville, Jeans for Genes, Abhi stores Ltd, One Stop, Sue Williams, Tina Stilwell Hunt, Rudi Evans, Genesis Capital Finance and Leasing 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 cancelled another 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 going ahead for The Conference weekend in July 2023, this will be reviewed again in the New Year regarding the safeguarding of getting together in person.

The charity has offered a new grant of up to £300 for families to apply for to include financial support during long stay hospital appointments each 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 and Hampshire.

**Restricted Income** - Grants 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 2023 due to Covid 19 restrictions and Maximus Foundation of £2500 towards the same Conference. We received a further £2840 this year from Jeans for Genes which we will also spend on the coming Conference, which increases our restricted total to £7956.66. With the deposit already paid to the hotel, this will be an incredible help to cover approximately half the costs of the event.

A report will be sent 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 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 2023.

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 2022 we held £58,117.23 in our accounts, £10,000 of this is reserved (which is an increase of £5000 from last year.) We have opened a fixed 12 months, no access, saving account with 3% interest so we can transfer the reserves of £10,000 into this account. We will review increasing this amount to £15,000 next year with the target of £20,000 the following year.

## **Zellweger UK - Annual Chairperson Report**

### **For the period 1<sup>st</sup> September 2021 - 31 August 2022**

I look back on our last running year proud of our team who have not only had the tail end of 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 77 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 2022 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 to turn as well as information with support for newly diagnosed families and ongoing support for existing families. We have also been able to provide memory jewellery for some of our bereaved families. We have given equipment grants as well as financial assistance grant for families for long hospital stays.

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 4th 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 measures 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.

### **Fundraising**

We have received an amazing amount of support from families, fundraisers and grant providers, with The Maximus Foundation providing us with a £2500 grant and Jeans for Genes with £2840. Dubs of Vanarchy with their ongoing support raising £1340.00 for this financial year alone, being Charity of the Year from a school raising £2371.17, cricket match raising £5233.00 and many more donations from families, friends and extended families. We are so grateful for the ongoing support from so many.

### **Supporters and collaborators**

We continue to be globally partnered with The GPPD (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 Schrader Lab, a team of researchers at the University of Exeter with outreach collaborations.

### **Finances**

The Charity made a profit of £17710.95, which is an improvement on last year in funds. 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 2022 and Balance Sheet for Year Ending August 2022.

	<b>Sep '21 - Aug 22</b>
<b>Ordinary Income/Expense</b>	
<b>Income</b>	
<b>Amazon Smile</b>	72.79
<b>Cake Sales</b>	62.50
<b>Charity of the Year</b>	2,371.17
<b>Club Fundraising</b>	
<b>Club Dubs of Vanarchy</b>	1,340.00
<b>Total Club Fundraising</b>	1,340.00
<b>Easyfundraising</b>	115.71
<b>Facebook champaigns</b>	
<b>Birthday Donation</b>	636.75
<b>Facebook champaigns - Other</b>	5,242.94
<b>Total Facebook champaigns</b>	5,879.69
<b>Fund Raising Events</b>	
<b>Cricket Fundraising Event</b>	5,233.00
<b>Eco Racing (Virtual balloons)</b>	166.75
<b>Ice Pop Sale</b>	40.00
<b>Marathons</b>	140.00
<b>Skydive</b>	770.00
<b>Total Fund Raising Events</b>	6,349.75

<b>Gifts and Donations Income</b>	
<b>Gift Aid</b>	202.50
<b>Gifts and Donations Income - Other</b>	<u>634.01</u>
<b>Total Gifts and Donations Income</b>	836.51
 <b>Grants - RESTRICTED INCOME</b>	
<b>Jeans for Genes Grant</b>	<u>2,840.00</u>
<b>Total Grants - RESTRICTED INCOME</b>	2,840.00
 <b>In Memory</b>	1,143.05
<b>King of the tin</b>	572.63
<b>Merchandise sold</b>	
<b>Christmas Cards</b>	5.50
<b>Face Masks</b>	60.00
<b>Mugs</b>	6.00
<b>Pens</b>	5.00
<b>Trolley coin</b>	3.00
<b>Merchandise sold - Other</b>	<u>74.32</u>
<b>Total Merchandise sold</b>	153.82
 <b>Paypal Giving Fund Uk</b>	
<b>Ebay sales</b>	40.00
<b>Paypal Giving Fund Uk - Other</b>	<u>58.75</u>
<b>Total Paypal Giving Fund Uk</b>	98.75
 <b>Pilates</b>	215.00
<b>Plant Sales</b>	60.00
<b>Postage and Packaging</b>	0.00
<b>Website Donations</b>	<u>470.25</u>
<b>Total Income</b>	22,581.62
 <b>Cost of Goods Sold</b>	
<b>Cost of Goods Sold</b>	<u>71.74</u>
<b>Total COGS</b>	<u>71.74</u>
 <b>Gross Profit</b>	22,509.88
 <b>Expense</b>	
<b>Awards and Grants</b>	
<b>Gym membership</b>	339.53
<b>Hospital Stay Assistance</b>	600.00
<b>Noncash Awards and Grants</b>	670.00
<b>Travel Insurance</b>	<u>160.47</u>
<b>Total Awards and Grants</b>	1,770.00

<b>Bank Charges</b>	
PayPal Charges	15.66
Virgin Card Fees	<u>8.55</u>
<b>Total Bank Charges</b>	24.21
<b>Computer and Internet Expenses</b>	224.38
<b>DBS- DISCLOSURE AND BAR</b>	23.00
<b>Disposed Assets</b>	150.00
<b>Fudraising Equipment</b>	
Fundraising Prizes	107.43
Fudraising Equipment - Other	<u>245.32</u>
<b>Total Fudraising Equipment</b>	352.75
<b>Miscellaneous Expense</b>	0.00
<b>Office Expense</b>	
Consumables	37.89
Software	1,728.13
Stationery	<u>6.59</u>
<b>Total Office Expense</b>	1,772.61
<b>Postage and Delivery</b>	159.92
<b>Printing and Reproduction</b>	144.99
<b>Travel and Meetings</b>	
Travel	<u>75.60</u>
<b>Total Travel and Meetings</b>	75.60
<b>Unauthorised Automated DDs</b>	0.00
<b>Wreaths</b>	<u>101.47</u>
<b>Total Expense</b>	<u>4,798.93</u>
<b>Net Ordinary Income</b>	<u>17,710.95</u>
<b>Profit for the Year</b>	<u><u>17,710.95</u></u>

	<b><u>31 Aug 22</u></b>
<b>ASSETS</b>	
<b>Fixed Assets</b>	
<b>Furniture and Fixtures</b>	
Medical Equipment	<u>1,944.00</u>
<b>Total Furniture and Fixtures</b>	<u>1,944.00</u>
<b>Total Fixed Assets</b>	1,944.00

<b>Current Assets</b>	
<b>Other Current Assets</b>	
<b>Stock</b>	<u>3,573.10</u>
<b>Total Other Current Assets</b>	3,573.10
<b>Cash at bank and in hand</b>	
<b>PayPal</b>	3,829.67
<b>Petty Cash</b>	10.00
<b>Zellweger UK</b>	<u>54,277.5</u>
<b>Total Cash at bank and in hand</b>	<u>58,117.2</u>
<b>Total Current Assets</b>	61,690.3
<b>Current Liabilities</b>	
<b>Accounts Payable</b>	
<b>Accounts Payable</b>	<u>16,055.2</u>
<b>Total Accounts Payable</b>	<u>16,055.2</u>
<b>Total Current Liabilities</b>	16,055.2
<b>NET CURRENT ASSETS</b>	<u>45,635.0</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>	<u>47,579.0</u>
<b>NET ASSETS</b>	<u><b>47,579.0</b></u>
<b>Capital and Reserves</b>	
<b>Merchandise</b>	2,280.96
<b>Unrestricted Net Assets</b>	27,587.1
<b>Profit for the Year</b>	<u>17,710.9</u>
<b>Shareholder funds</b>	<u><b>47,579.0</b></u>

Signed: Miss Kerry Hughes - Treasurer



Signed: Mrs N Anderson-Hunt – Chairperson

