

# **PMSF UK ANNUAL REPORT & AGM MINUTES**

AGM Held, Sun 15<sup>th</sup> January 2023, 14:30-15:30 via Zoom

#	Agenda Item	Presenter	Notes
1	Welcome / Introductions	Penny	<ul style="list-style-type: none"> <li>Attendees were – Penny Bradley (T) (Chair), Alison Turner (T), Giles Bradley (T), Lynda White (T), Natalie James (T), Sarah Bickerstaffe (T)</li> <li>6 trustees, shown as (T) above (min 2 required)</li> </ul>
2	Regional Membership Status	Lynda / Alison	<ul style="list-style-type: none"> <li>Now 320 region 6 members in UK/Ireland (as of Fri 6/1/23) (was 292 at last AGM in Nov 2021)</li> </ul>
3	List of achievements in 2022	Giles	<ul style="list-style-type: none"> <li>Summary of 2022 achievements approved and will be shared with the PMSF UK communication</li> <li>Photo highlights of the last PMSF UK year discussed</li> </ul>
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> <li>Draft accounts presented for review and agreed</li> <li>Will be presented for Independent Examination and then submitted to Charity Commission before the deadline of July 2023.</li> </ul>
5	Presented for agreement: <ul style="list-style-type: none"> <li>a. Confirmation of Charity Objectives</li> <li>b. Confirmation of trustees</li> <li>c. Review of Charity Policies</li> <li>d. Plans for next year</li> </ul>	All	<ul style="list-style-type: none"> <li>Agreed. See separate slide</li> <li>UK wide Family Day likely to be held in 2025 to be in alternate years with the Global Foundation (to be confirmed). Will continue Regional Events and potential Family Day meet-up (details to be confirmed, open to all UK families)</li> </ul>
6	Any other business	Penny to chair	
7	Closing	Penny	

# Agenda Item 3: Key achievements for 2021-2022

## Key Achievements and Performance Highlights – for the year to 30<sup>th</sup> September 2022

This is now our **8<sup>th</sup> full year as a charity!**

Our community has grown to **320 people in the UK and Ireland with PMS** now. As a reminder, it was just over 100 when we began as a registered charity in 2014.

Highlights for this financial year include:

- **More financial Awards made to families than ever before (to more families than ever)** – over 200 payments in total during the year to over 100 different families, incl. over 40 Covid-19 support awards made in January 2022. Since beginning the awards, they have benefited over 150 of our UK/Ireland families
- **More funds raised for PMSF UK than ever before** – over 50 direct donations and 948 individual JustGiving donations in the year. More than 20 new JustGiving fundraising pages created for walking (incl. one for 50k and another in kilts), cycling, sky-diving, running, Christmas lights
- **Shine Green and PMS Awareness Day** – lighting up 14 different UK landmarks to mark the global Awareness Day in October 2022 (& a radio interview on BBC Radio Lancashire!)
- **Regional Family Days** held in the North, Midlands, South, London and Ireland, attended by approx. **50 UK/Ireland families**
- **More PMSF UK merchandise sold than ever before** – including Christmas jumpers, Christmas cards and our PMSF UK 'We wear our genes differently' t-shirts and hoodies
- Continued **support for Phelan Lucky**, incl. a UK bulk order
- **Website redesigned and relaunched in 2021** – more website views than last year, 6,771 users visiting and over 20,000 individual page views (up from 13,157 in 2021)
- **Bigger Social Media presence than ever** – growing presence and more posts shared than ever before. We now have 600 public Facebook page followers, an active closed Facebook group for families, 276 Instagram followers and a presence now on Twitter as well.

# Agenda Item 3: A few highlights of our PMSF UK year





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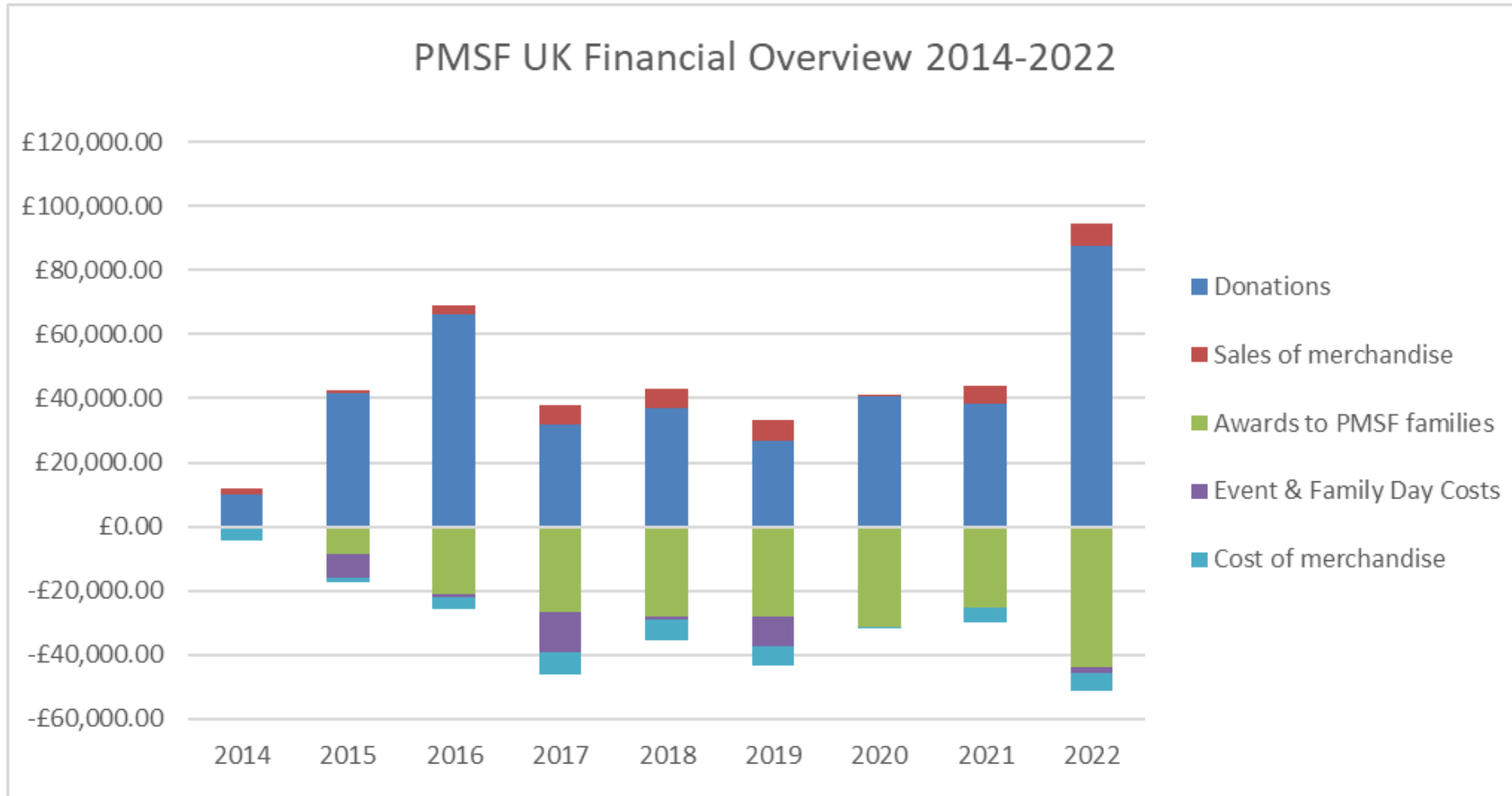


# Agenda Item 3: A few highlights of our PMSF UK year



# Agenda Item 4: Financial Highlights for 2021-22

- The year to end of September 2022 is by far the biggest year we've ever had – for donations, merchandise and awards





# Agenda Item 4: Financial Results Detail

Will be submitted for Independent Examination and then to Charity Commission



Phelan-McDermid Syndrome Foundation UK

This has been the charity's best year ever... And our healthy cash balance means we are continuing the great work (Family Days, Awards etc.) in 2022/3

- **The most awards to our families we have ever made**
- **The most donations we've ever received**
- **The best JustGiving year ever**
- **More Regional Family Days held than ever** across most of our Regions
- **The most merchandise we've ever sold**
- Donations made to the **Global Foundation** and **PMSF Research Fund**

We continue to manage our out-goings carefully – which are mainly for the website, admin support and postal costs as well as merchandise and fundraising event places

	This Year (2022) 1-Oct-21 to 30-Sep-22	2021 1-Oct-20 to 30-Sep-21
<b>Cash</b>		
Opening cash balance	£37,863.12	£27,459.32
Closing cash balance [bank & PayPal]	£71,842.83	£37,863.12
<b>Receipts</b>	£94,538.40	£43,749.49
Donations	£87,488.81	£38,218.75
<i>Restricted funds (1)</i>		
<i>Direct (2)</i>	£56,216.89	£9,847.49
<i>JustGiving</i>	£28,920.76	£25,988.60
<i>VirginGiving [Closed now]</i>	£0.00	£0.00
<i>FaceBook</i>	£477.85	£1,422.07
<i>Amazon</i>	£548.10	£604.79
<i>PayPal</i>	£1,260.05	£314.16
<i>Benevity</i>	£0.00	£0.00
<i>EasyFundraising</i>	£65.16	£41.64
Sales of merchandise (3)	£7,049.59	£5,530.74
<i>Sales of merchandise (Bank credits)</i>	£2,230.90	£4,083.20
<i>Sales of merchandise (PayPal)</i>	£4,818.69	£1,447.54
<b>Payments</b>	-£60,558.69	-£33,345.69
Awards to PMSF families	-£43,725.05	-£25,375.71
<i>Awards Programme (excl. Travel)</i>	-£43,725.05	-£25,375.71
<i>Travel awards</i>		
Research Awards (to US Foundation)	-£2,070.08	£0.00
Donation to PMSF (US Foundation)	-£1,000.00	£0.00
Website costs	-£732.25	£0.00
Event costs (incl. Family Days)	-£1,948.86	£0.00
Purchase of Charity Event Places	-£1,688.01	-£530.00
Purchase of merchandise	-£5,629.44	-£4,737.59
Purchase of printed leaflets	£0.00	£0.00
Postal expenses	-£716.60	-£505.13
JustGiving & Virgin costs	-£561.60	-£561.60
Other expenses (4)	-£2,486.80	-£1,635.66

# Agenda Item 4: 2021-22 Donations Summary

- Total donations of **£87,488.71** – from the following sources:
  - **£28,921 raised via JustGiving** (breaking last year's record for the most we have ever raised via JustGiving, consisting of **948 individual donations** made via JustGiving during the financial year)
  - **£56,217 received as direct donations** (including a very generous legacy donation)
  - **£2,351 via other platforms** (Facebook, Amazon, PayPal, Easyfundraising)
- **We appreciate every donation to PMSF UK. - Thank you to all of our supporters**
- We would like to say a special thank you to a number of significant fundraising achievements and donations from 2021-2022, including those who took part in Run Like a Hero and the Glasgow Kiltwalk.
  - ✓ Bec Ecclestone, Vicky Lewis and Tim Hill Royal Parks Half Marathon
  - ✓ Cooper / Rhodes Family
  - ✓ Emma Lacey Jurassic Coast Challenge
  - ✓ Flynn's Tour de Moor
  - ✓ Heather Hodson, Dawn Lamin and Steve Lamin's 50km Walk (& Castlegate Financial)
  - ✓ Holly Lodge Christmas Lights
  - ✓ James Picker
  - ✓ Janet Margaret Smith & Carballo family
  - ✓ Lisa (Wilton) and Gary's Yorkshire Three Peaks
  - ✓ Matthew Chambers Ride London
  - ✓ Nicola McVennon & colleagues at Ikon Design
  - ✓ Sammy Coomber
  - ✓ Sean and Sophie Farrell Sky Dive (& HSBC)
  - ✓ Stuart and Helen Leighton
  - ✓ Team Pond Sky Dive
  - ✓ Townsend Family



# Agenda Item 5: Items for agreement

Item	Proposal for agreement
a. Confirmation of Charity Objectives	<ul style="list-style-type: none"><li>• No change to the charity's Objectives</li></ul>
b. Confirmation of Trustees	<ul style="list-style-type: none"><li>• For noting: Renewal of 3 year Trustee term (until 2025) for Lynda</li><li>• For completeness, 6 trustees remain: Alison, Giles, Lynda, Natalie, Penny, Sarah.</li></ul>
c. Review of Charity Policies	<ul style="list-style-type: none"><li>• No change to the charity's Policies</li></ul>
d. Plans for next year	<ul style="list-style-type: none"><li>• Plan to continue existing activities (building awareness, regional family days, focus on awards to PMS families, donate to &amp; support research)</li><li>• Hold further regional gatherings in 2023 (as we did in 2022)</li><li>• UK wide Family Day likely to be held in 2025 to be in alternate years with the Global Foundation (to be confirmed). Will continue Regional Events and potential Family Day meet-up open to all UK families in 2023 (details to be confirmed)</li></ul>

# Agenda Items 6 & 7

#	Agenda Item	Presenter	Notes
1	Welcome / Introductions	Penny	<ul style="list-style-type: none"> <li>Confirmation of trustee attendance (min 2 required)</li> </ul>
2	Regional Membership Status	Lynda / Alison	<ul style="list-style-type: none"> <li>Now 292 region 6 members in UK/Ireland (as of Tue 26/10/21) (was 281 at last AGM in Nov 2020)</li> </ul>
3	List of achievements in 2022	Giles	<ul style="list-style-type: none"> <li>Summary of 2021 achievements noted</li> <li>Recognition in appreciation of PMSF UK Awards noted</li> </ul>
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> <li>Draft accounts presented for review</li> <li>Subject to agreement, will be presented for Independent Examination and then submitted to Charity Commission before the deadline of July 2022.</li> </ul>
5	Presented for agreement: a. Confirmation of Charity Objectives b. Confirmation of trustees c. Review of Charity Policies d. Plans for next year	All	<ul style="list-style-type: none"> <li>See separate slide</li> </ul>
6	Any other business	Penny to chair	
7	Closing	Penny	





Phelan McDermid Syndrome UK	1157423
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## Receipts and payments accounts

For the period from	1-Oct-21	To	30-Sep-22
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### Section A Receipts and payments

	Unrestricted funds to the nearest £	Restricted funds to the nearest £	Endowment funds to the nearest £	Total funds to the nearest £
<b>A1 Receipts</b>				
Donations	87,489	-	-	87,489
Merchandise Sales	7,050	-	-	7,050
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
<b>Sub total</b> (Gross income for AR)	94,538	-	-	94,538
<b>A2 Asset and investment sales, (see table).</b>				
	-	-	-	-
	-	-	-	-
<b>Sub total</b>	-	-	-	-
<b>Total receipts</b>	94,538	-	-	94,538
<b>A3 Payments</b>				
Awards to Families	43,725	-	-	43,725
Research Awards	2,070	-	-	2,070
US Donation	1,000	-	-	1,000
Website costs	732	-	-	732
Events	1,949	-	-	1,949
Charity Event Places Purchase	1,688	-	-	1,688
Merchandise Purchase	5,629	-	-	5,629
Other	3,765	-	-	3,765
	-	-	-	-
<b>Sub total</b>	60,559	-	-	60,559
<b>A4 Asset and investment purchases, (see table)</b>				
	-	-	-	-
	-	-	-	-
<b>Sub total</b>	-	-	-	-
<b>Total payments</b>	60,559	-	-	60,559
<b>Net of receipts/(payments)</b>	33,980	-	-	33,980
<b>A5 Transfers between funds</b>	-	-	-	-
<b>A6 Cash funds last year end</b>	37,863	-	-	37,863
<b>Cash funds this year end</b>	71,843	-	-	71,843

## Section B Statement of assets and liabilities at the end of the period

Categories	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
<b>B1 Cash funds</b>	Cash in bank / PayPal	71,843	-
		-	-
		-	-
	<b>Total cash funds</b>	71,843	-
	(agree balances with receipts and payments account(s))	OK	OK
<b>B2 Other monetary assets</b>		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
		-	-
<b>B3 Investment assets</b>			-
			-
			-
			-
			-
<b>B4 Assets retained for the charity's own use</b>			-
	PMSF merchandise stock value, all items	Unrestricted	-
			-
			-
			-
			-
			-
			-
			-
<b>B5 Liabilities</b>			-
			-
			-
			-
			-
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	
		Giles Bradley	



**CC16a**



**Last year**

**to the nearest £**

<b>38,219</b>
<b>5,531</b>
-
-
-
-
-
-
<b>43,749</b>

-
-

<b>43,749</b>
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<b>25,376</b>
-
-
-
-
<b>530</b>
<b>4,738</b>
<b>2,702</b>
-
<b>33,346</b>

-

<b>33,346</b>
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<b>10,404</b>
-
<b>27,459</b>
<b>37,863</b>



**Endowment  
funds**  
to nearest £

-
-
-
-

OK

**Endowment  
funds**  
to nearest £

-
-
-
-
-
-

**Current value  
(optional)**

-
-
-
-
-

**Current value  
(optional)**

-
-
-
-
-
-
-
-
-

**When due  
(optional)**


Date of  
approval


## **Independent examiner's report to the trustees of PMSF UK**

I report to the trustees on my examination of the accounts of PMSF UK for the year ended 30 September 2023.

### **Responsibilities and basis of the report**

As the charity trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of PMSF UK's accounts carried out under section 145 of the 2011 Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

### **Independent examiner's statement**

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of PMSF UK as required by section 130 of the Act, or
2. the accounts do not accord with those records

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

Signed:



Name: Elizabeth Cain

Relevant professional qualification or membership of professional bodies: ACA qualification from the ICAEW

Address: 33 Hoodcote Gardens, London, N21 2NG

Date: 26 May 2023