

PMSF UK ANNUAL REPORT & AGM MINUTES

AGM held Sat 23rd March 2024, 10:00-11:00 via Zoom

AGM Minutes

#	Agenda Item	Presenter	Summary of meeting minutes
1	Welcome / Introductions	Alison	<ul style="list-style-type: none"> Confirmation of 5 trustees in attendance (min 2 required) 11 meeting attendees in total
2	Regional Membership Status	Lynda / Alison	<ul style="list-style-type: none"> Now 360 region 6 members in UK/Ireland (as of Thu 14/3/24) (was 315 at last AGM in Nov 2022) Changes in the relationship with the Global Foundation were explained by Alison
3	List of achievements in 2023	Giles / All	<ul style="list-style-type: none"> Summary of 2022-23 achievements noted
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> Draft accounts presented for review – They will now be presented for Independent Examination and then submitted to Charity Commission
5	Presented for agreement: <ul style="list-style-type: none"> a. Confirmation of Charity Objectives b. Confirmation of trustees c. Review of Charity Policies d. Plans for next year 	Alison	<ul style="list-style-type: none"> See page 8
6	Any other business	Alison to chair	<ul style="list-style-type: none"> Research update provided – SHANK3 gene therapy information on the Global Foundation website; Potential Insulin study underway at King's College London with PMS patients registered in Spring 2025 (we'll keep you posted) Action taken by PMSF UK to review oversight of UK Facebook closed group
7	Closing	Alison	<ul style="list-style-type: none"> Alison closed the meeting A recording of the Zoom meeting will be provided to attendees, if requested

Agenda Item 3: Key achievements for 2022-2023

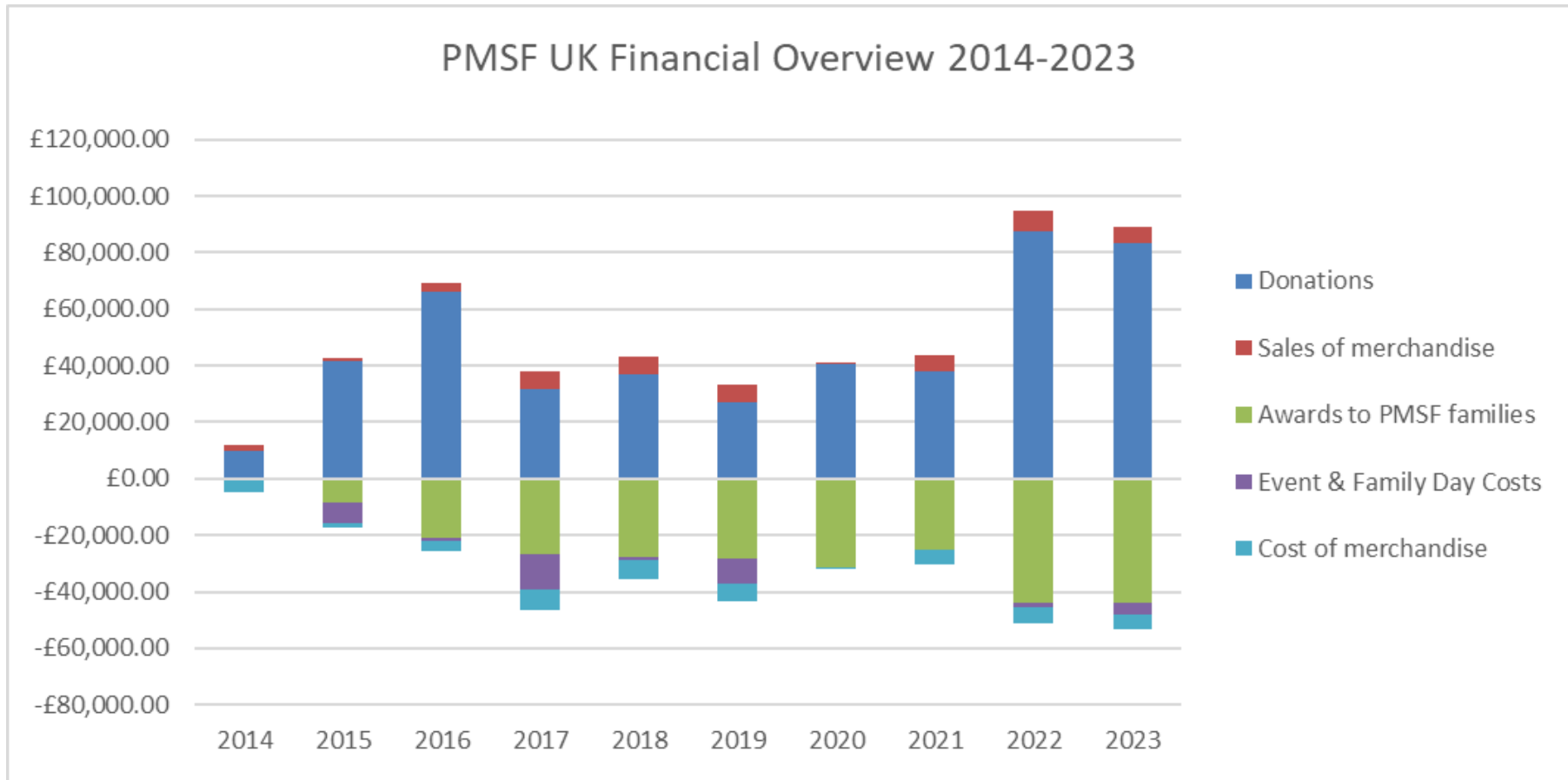
Section D	
Achievements and Performance – to 30-Sep-2023	<p>This is now our 9th full year as a charity, heading for our 10th anniversary in June 2024!</p> <p>Our community has grown to 360 people in the UK and Ireland with PMS now. As a reminder, it was just over 100 when we began as a registered charity in 2014.</p> <p>Highlights for this financial year include:</p> <ul style="list-style-type: none">• More financial Awards made to families than ever before (to more families than ever) – over 160 payments in total during the year to over 150 different applicants• A really successful year of fundraising – including generous individual donations, several marathon and other run entries, Christmas lights, walks, family events and fundraisers• Shine Green in October 2022 and October 2023• Regional Family Days held in London, the North-West, Midlands, South and Ireland – and a significant family event held at Alton Towers in October 2023 (technically in the current next financial year)• A successful year of PMSF UK merchandise sales – including Christmas jumpers, Christmas cards and other PMSF UK branded items• Continued support for Phelan Lucky, incl. a UK bulk order• Continued support for our website as a key resource for our families and to drive awareness• Continued our Social Media presence – we now have >640 public Facebook page followers, and active closed Facebook group for families, 330 Instagram followers and a presence now on Twitter as well.

Agenda Item 3: A few highlights of our PMSF UK year from our social media channels



Agenda Item 4: Financial Highlights for 2022-23

- The year to end of September 2023 has been another very strong year for the charity, comfortably our 2nd best ever, even breaking (just!) 2022's record for financial awards



Agenda Item 4: Financial Results Detail

Finalised in July 2024, following Independent Examination

This has been another very strong year for the charity. And our strong financial position has meant that we have been able to continue this work into 2023-2024 already.

- **The most awards to our families we have ever made (a new record)**
- **Our 2nd biggest year ever for donations**
- **Five Regional Family Days held**
- **Another strong year of merchandise sales**
- 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 (2023) 1-Oct-22 to 30-Sep-23	2022 1-Oct-21 to 30-Sep-22
Cash		
Opening cash balance	£71,842.83	£37,863.12
Closing cash balance [bank & PayPal]	£100,003.06	£71,842.83
Receipts	£89,017.25	£94,538.40
Donations	£83,464.76	£87,488.81
<i>Restricted funds (1)</i>		
<i>Direct (2)</i>	£63,786.78	£56,216.89
<i>JustGiving</i>	£18,455.79	£28,920.76
<i>VirginGiving [Closed now]</i>	£0.00	£0.00
<i>FaceBook</i>	£379.07	£477.85
<i>Amazon</i>	£730.08	£548.10
<i>PayPal</i>	£38.25	£1,260.05
<i>Benevity</i>	£0.00	£0.00
<i>EasyFundraising</i>	£74.79	£65.16
Sales of merchandise (3)	£5,552.49	£7,049.59
<i>Sales of merchandise (Bank credits)</i>	£2,915.00	£2,230.90
<i>Sales of merchandise (PayPal)</i>	£2,637.49	£4,818.69
Payments	-£60,857.02	-£60,558.69
Awards to PMSF families	-£43,807.25	-£43,725.05
<i>Awards Programme (excl. Travel)</i>	-£43,807.25	-£43,725.05
<i>Travel awards</i>		
Research Awards (to US Foundation)	-£2,000.00	-£2,070.08
Donation to PMSF (US Foundation)	-£1,168.46	-£1,000.00
Website costs		-£732.25
Event costs (incl. Family Days)	-£4,302.20	-£1,948.86
Purchase of Charity Event Places	-£1,015.00	-£1,688.01
Purchase of merchandise	-£5,067.35	-£5,629.44
Purchase of printed leaflets	£0.00	£0.00
Postal expenses	-£471.23	-£716.60
JustGiving & Virgin costs	-£561.60	-£561.60
Other expenses (4) (incl. website from 2023)	-£2,463.93	-£2,486.80

Agenda Item 4: 2022-23 Donations Summary

- Total donations of **£83,464.76** – from the following sources:
 - **£18,456 raised via JustGiving** consisting of **731 individual donations** made via the platform during the financial year
 - **£63,787 received as direct donations** (including a very generous legacy donation)
 - **£1,222 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 2022-2023
 - ✓ The Allen Family
 - ✓ Karon Banks
 - ✓ Leza Bliss
 - ✓ Paul Brockway
 - ✓ Sammy Coomber
 - ✓ Rebecca Ecclestone
 - ✓ Jemima Elliot-Garwood
 - ✓ Hillway Christmas Lights
 - ✓ Heather Hodson, Dawn Lamin and Steve Lamin's (& Castlegate Financial)
 - ✓ Kellie Littmoden and Helen
 - ✓ Craig O'Reilly
 - ✓ Shine Green
 - ✓ The Ruddock Family
 - ✓ Sophia Williams

Agenda Item 5: Items for agreement

Item	Proposals and agreements
a. Confirmation of Charity Objectives	<ul style="list-style-type: none">• No change to the charity's Objectives
b. Confirmation of Trustees	<ul style="list-style-type: none">• For noting: Renewal of 3 year Trustee term (until 2026) for Alison• For noting: Confirmation of Alison as Chair• For noting: Confirmation of Tanith as Trustee• For noting: Giles's Trustee term will not be renewed, so steps down as Trustee• For noting: Thank you to Penny Bradley and Sarah Bickerstaffe for their significant contributions as Trustees• For completeness, 4 trustees remain: Alison, Lynda, Natalie, Tanith
c. Review of Charity Policies	<ul style="list-style-type: none">• No change to the charity's Policies – although new policies to be created for Complaints and Vulnerable Adults
d. Plans for next year	<ul style="list-style-type: none">• Plan to continue existing activities (building awareness, regional family days, focus on awards to PMS families, donate to & support research)• Tea for Ten, a series of tea parties across the U.K. and Ireland organised by families to celebrate our 10th anniversary in June 2024• Next UK-wide Family Day planned for 2025



Phelan McDermid Syndrome UK

1157423

Receipts and payments accounts

CC16a

For the period
from

1-Oct-22

To

30-Sep-23

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 £	Last year to the nearest £
A1 Receipts					
Donations	83,465	-	-	83,465	87,489
Merchandise Sales	5,552	-	-	5,552	7,050
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	89,017	-	-	89,017	94,538
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	89,017	-	-	89,017	94,538
A3 Payments					
Awards to Families	43,807	-	-	43,807	43,725
Research Awards	2,000	-	-	2,000	2,070
US Donation	1,168	-	-	1,168	1,000
Website costs	-	-	-	-	732
Events	4,302	-	-	4,302	1,949
Charity Event Places Purchase	1,015	-	-	1,015	1,688
Merchandise Purchase	5,067	-	-	5,067	5,629
Other	3,497	-	-	3,497	3,765
	-	-	-	-	-
Sub total	60,857	-	-	60,857	60,559
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	60,857	-	-	60,857	60,559
Net of receipts/(payments)	28,160	-	-	28,160	33,980
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	71,843	-	-	71,843	37,863
Cash funds this year end	100,003	-	-	100,003	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 £	Endowment funds to nearest £
B1 Cash funds	Cash in bank / PayPal	100,003	-	-
		-	-	-
		-	-	-
	Total cash funds	100,003	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
		Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
B2 Other monetary assets		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets		Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use		Fund to which asset belongs	Cost (optional)	Current value (optional)
	PMSF merchandise stock value, all items	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities		Fund to which liability relates	Amount due (optional)	When due (optional)
			-	
			-	
			-	
			-	
Signed by one or two trustees on behalf of all the trustees	Signature	Print Name	Date of approval	
		Giles Bradley		

Phelan-McDermid Syndrome Foundation UK (PMSF UK)

Independent Examiner's Report to the Trustees For The Year To 30 September 2023

Responsibilities and basis of report

I report to the Trustees on my examination of the accounts of the above charity for the year ended 30 September 2023. As the charity's 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 the Charity's accounts carried out under section 145 of the 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 which gives me cause to believe that in, any material respect:

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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.

Tin Nwe Myint FCCA

Delta Accountancy Advice Ltd
8 Margaret Avenue
St Albans
Hertfordshire
AL3 5TE

Date: