

PMSF UK ANNUAL REPORT & AGM MINUTES

AGM held Sat 25th January 2025, 10:00-11:00 via Zoom

#	Agenda Item	Presenter	Notes
1	Welcome / Introductions	Alison	<ul style="list-style-type: none"> Confirmation of attendance – all trustees present, plus 2 further attendees
2	Regional Membership Status	Lynda / Tanith	<ul style="list-style-type: none"> Now 384 region 6 members in UK/Ireland (as of 30/12/24) (was 360 at last AGM in March 2024) Update on PMSF International from Alison
3	List of achievements in 2024	Alison	<ul style="list-style-type: none"> Summary of achievements 2023-2024 noted
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> Draft accounts presented for review – and will go forward now to be presented for Independent Examination and submitted to Charity Commission before the deadline of July 2025.
5	Presented for agreement: <ol style="list-style-type: none"> Confirmation of Charity Objectives Confirmation of trustees Review of Charity Policies Plans for next year 	Alison	<ul style="list-style-type: none"> Complaints policy to be re-confirmed to members
6	Any other business	Alison to chair	<ul style="list-style-type: none"> Kings College insulin study grant update provided by Alison. This may move forward in 2025, looking for 100-300 families to participate. Nasal insulin may increase learning, understanding and social skills – with future treatment subject to successful clinical trial. Update given on regional reps and plans for Family Days. PMSF UK Scotland rep role open
7	Closing	Alison	<ul style="list-style-type: none"> Alison closed the meeting

Agenda Item 3: Key achievements for 2023-2024

Section D	
Achievements and Performance – to 30-Sep-2024	<p>The charity celebrated its 10th anniversary in 2024 – marked across our community with “Tea for Ten” parties.</p> <p>Our community has grown to 384 people in the UK and Ireland 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 190 payments in total during the year• A really successful year of fundraising – including the most successful year on JustGiving ever for the charity, over 1,100 individual JustGiving donations for, amongst other things, walks, climbs hikes, marathons, family fundraisers, tea parties, triathlons and bathing in baked beans!• Shine Green in October 2024• Local events for “Tea for Ten” across all of the UK and Ireland, and a significant Family Day held at Alton Towers in October 2023 (technically financial year 2023-24)• Another successful year of PMSF UK merchandise sales and another successful bulk order to support Phelan Lucky• 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.

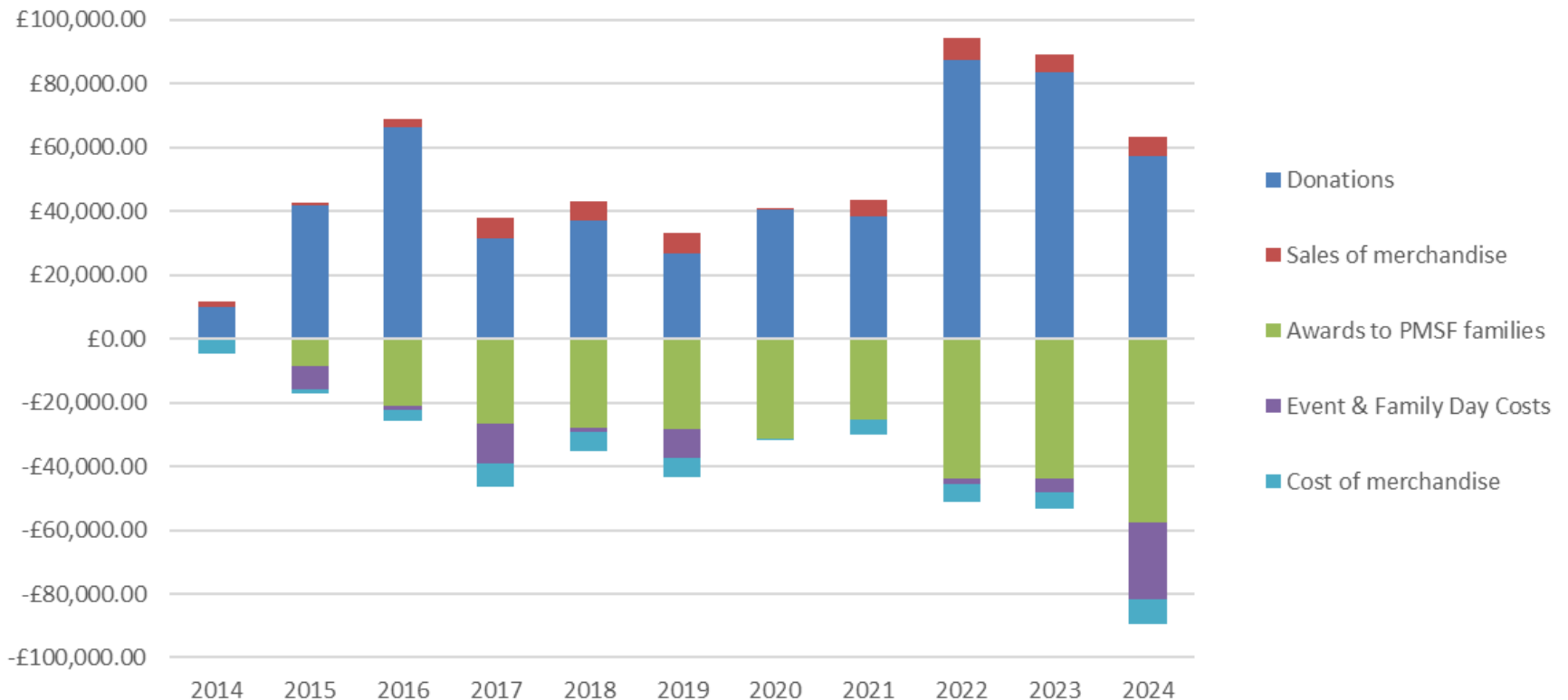
Agenda Item 3: A few highlights of our PMSF UK year from our social media channels



Agenda Item 4: Financial Highlights for 2023-24

- The last year has been the largest in terms of Awards and the 2023 Alton Towers Family Day in the charity's history.

PMSF UK Financial Overview 2014-2024



Agenda Item 4: Financial Results Detail

Will be submitted for Independent Examination and then to Charity Commission



Phelan-McDermid Syndrome Foundation UK

The strong financial position at the start of financial year 2023 has enabled the charity to provide record support to the community

- **The most awards to our families we have ever made (a new record, beating even last year)**
- **Our best-ever year for JustGiving fundraising (the only stronger years involved large legacy donations)**
- **The most ambitious Family Day ever held at Alton Towers**
- **“Tea for Ten” to celebrate the charity’s 10th anniversary**
- A donations to help set up a **new International PMSF** organisation

We continue to manage our out-goings carefully. This year’s increase in expenses including now paying for an external accountant and legal costs for a one-off issue which has now been resolved.

	This Year (2024) 1-Oct-23 to 30-Sep-24	This Year (2023) 1-Oct-22 to 30-Sep-23
Cash		
Opening cash balance	£100,003.06	£71,842.83
Closing cash balance [bank & PayPal]	£59,524.91	£100,003.06
Receipts	£63,259.45	£89,017.25
Donations	£57,404.42	£83,464.76
<i>Restricted funds (1)</i>		
<i>Direct (2)</i>	£19,966.20	£63,786.78
<i>JustGiving</i>	£35,950.75	£18,455.79
<i>VirginGiving [Closed now]</i>	£0.00	£0.00
<i>FaceBook</i>	£44.03	£379.07
<i>Amazon</i>	£0.00	£730.08
<i>PayPal</i>	£1,029.92	£38.25
<i>Benevity</i>	£372.07	£0.00
<i>EasyFundraising</i>	£41.45	£74.79
Sales of merchandise (3)	£5,855.03	£5,552.49
<i>Sales of merchandise (Bank credits)</i>	£3,589.63	£2,915.00
<i>Sales of merchandise (PayPal)</i>	£2,265.40	£2,637.49
Payments	-£103,737.60	-£60,857.02
Awards to PMSF families	-£57,702.00	-£43,807.25
<i>Awards Programme (excl. Travel)</i>	-£57,702.00	-£43,807.25
<i>Travel awards</i>		
Research Awards (to US Foundation)		-£2,000.00
Donation to PMSF (US Foundation)		-£1,168.46
International Foundation	-£4,314.44	
Website costs	-£731.70	
Event costs (incl. Family Days)	-£23,889.68	-£4,302.20
Purchase of Charity Event Places	-£444.00	-£1,015.00
Purchase of merchandise	-£7,783.66	-£5,067.35
Purchase of printed leaflets	-£825.00	£0.00
Postal expenses	-£507.11	-£471.23
JustGiving & Virgin costs	-£561.60	-£561.60
Other expenses (4) (incl. website from 2023)	-£6,978.41	-£2,463.93

Agenda Item 4: 2023-24 Donations Summary

- Total donations of **£57,404** – from the following sources:
 - **£35,951 raised via JustGiving** consisting of 1,183 **individual donations (was 731 last year)** made via the platform
 - **£19,966 received from 85 direct donations** (including money raised from “Tea for Ten” parties)
 - **£1,487 via other platforms** (PayPal, Benevity, Easyfundraising, Facebook)
- **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 2023-24
 - ✓ The Allen Family
 - ✓ Karon Banks
 - ✓ Paul Brockway
 - ✓ Lisa Hollinger
 - ✓ Natalie Lingard
 - ✓ Matthew Barclay
 - ✓ Chris Phillips
 - ✓ Kirsty And Andrea Phillips
 - ✓ Hillway Christmas Lights
 - ✓ Craig O'Reilly
 - ✓ Nationwide Building Society
 - ✓ Quadient
 - ✓ Bolton School
 - ✓ Harrison Frank Foundation [£5k]
 - ✓ Penny Bradley
 - ✓ Rosie Bovaird
 - ✓ Martha Provan

Agenda Item 5: Items for agreement

Item	Proposal for agreement
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">No change to TrusteesFor 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 PoliciesThe complaints policy has been reviewed and is summarized below.<ul style="list-style-type: none">Any complaints should directed to the postal address or email address of the charity (info@pmsf.org.uk)Complaints will be responded to in writing by one of the Trustees (by default – the Chair of Trustees or an agreed delegate)Should you require further escalation, PMSF UK is a registered charity with the UK Charity Commission. Details can be found at: https://www.gov.uk/complain-about-charitySuspensions of impropriety within the Trustees should be shared / discussed openly – with escalation to the Chair of Trustees initially. The charity supports the whistle-blower route via the Charity Commission if that were ever considered necessary (whistleblowing@charitycommission.gsi.gov.uk)
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)A UK/I-wide Family Day is planned for 10th May 2025, with venue and logistics details still to be confirmed

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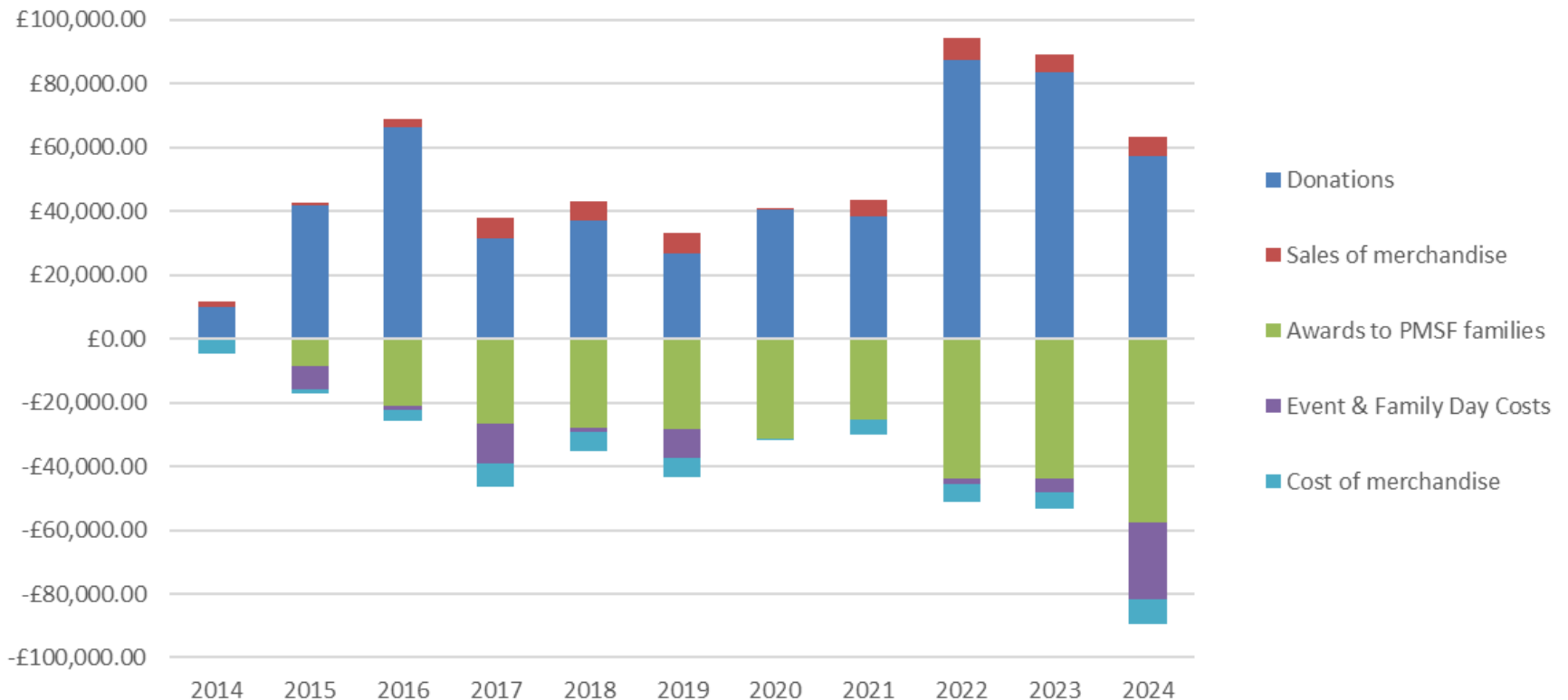
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Phelan-McDermid Syndrome Foundation UK (PMSF UK)

Independent Examiner's Report to the Trustees For The Year To 30 September 2024

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 2024. 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: 28 July 2025