

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales · Charity number 1157423

Details

Other names PMSF UK

Status Registered

Legal form CIO

Registered 2014-06-10

Register [View on the Charity Commission register](#)

Contact

Address 99 Highgate West Hill
London
N6 6NR

Phone 02074194554

Email info@pmsf.org.uk

Website www.pmsf.org.uk

Activities

Objects: THE OBJECT OF THE CIO IS:THE RELIEF OF NEEDS OF PEOPLE WHO HAVE BEEN DIAGNOSED WITH PHELAN-MCDERMID SYNDROME (CHROMOSOME 22Q13.3 DELETION) AND THEIR FAMILIES, IN PARTICULAR BUT NOT EXCLUSIVELY BY PROVIDING SUPPORT, FAMILY DAYS, INFORMATION, FINANCIAL GRANTS FOR DIFFERENT THERAPIES FOR THE PERSON WITH THE SYNDROME AND RESEARCH ENDORSED BY THE INTERNATIONAL PHELAN-MCDERMID SYNDROME FOUNDATION.

Activities: Relief of the needs of people who have been diagnosed with PMS and their families in the UK and Ireland ? in particular, but not exclusively, by providing support, family days, information, financial grants for different therapies for the person with the syndrome and research endorsed by the international Phelan-McDermid Syndrome Foundation

Classification

- **How:** Makes Grants To Individuals, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Ireland
- Northern Ireland
- Scotland
- Camden

Finances

Period end	Income	Expenditure	Assets	Employees
2024-09-30	£63,259	£103,738	-	-
2023-09-30	£89,017	£60,857	-	-
2022-09-30	£94,538	£60,559	-	-
2021-09-30	£43,749	£33,346	-	-
2020-09-30	£41,138	£35,805	-	-

Trustees

Name	Role	Appointed
ALISON JANE TURNER	Chair	2017-11-11
LYNDA WHITE		2016-11-12
Natalie James		2018-11-17
Tanith Sherwood		2024-03-13

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales - Charity number 1157423

Accounts

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

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.

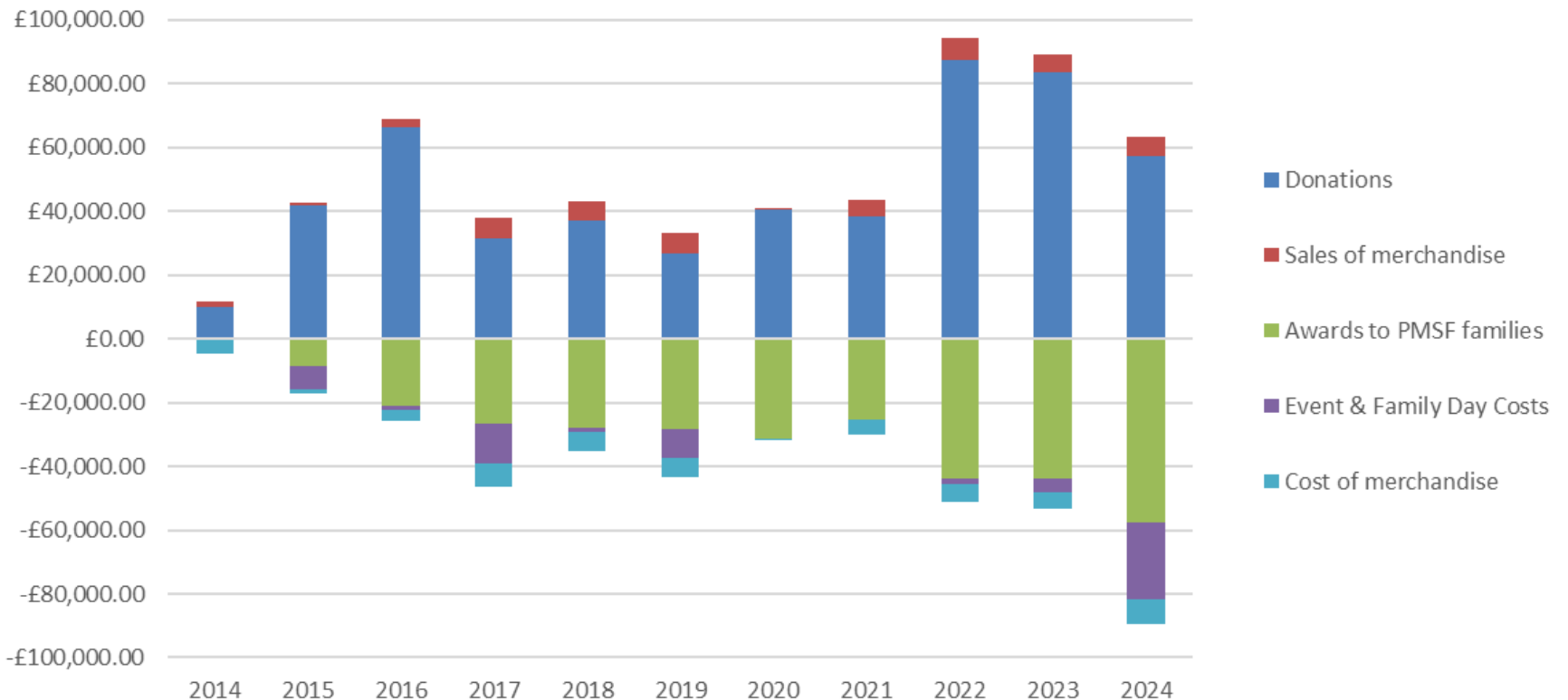
Agenda Item 3: A few highlights of our PMSF UK year from our social media channels



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



Phelan-McDermid Syndrome Foundation UK

- 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



Phelan-McDermid Syndrome Foundation UK

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 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• The 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-charity• Suspicions 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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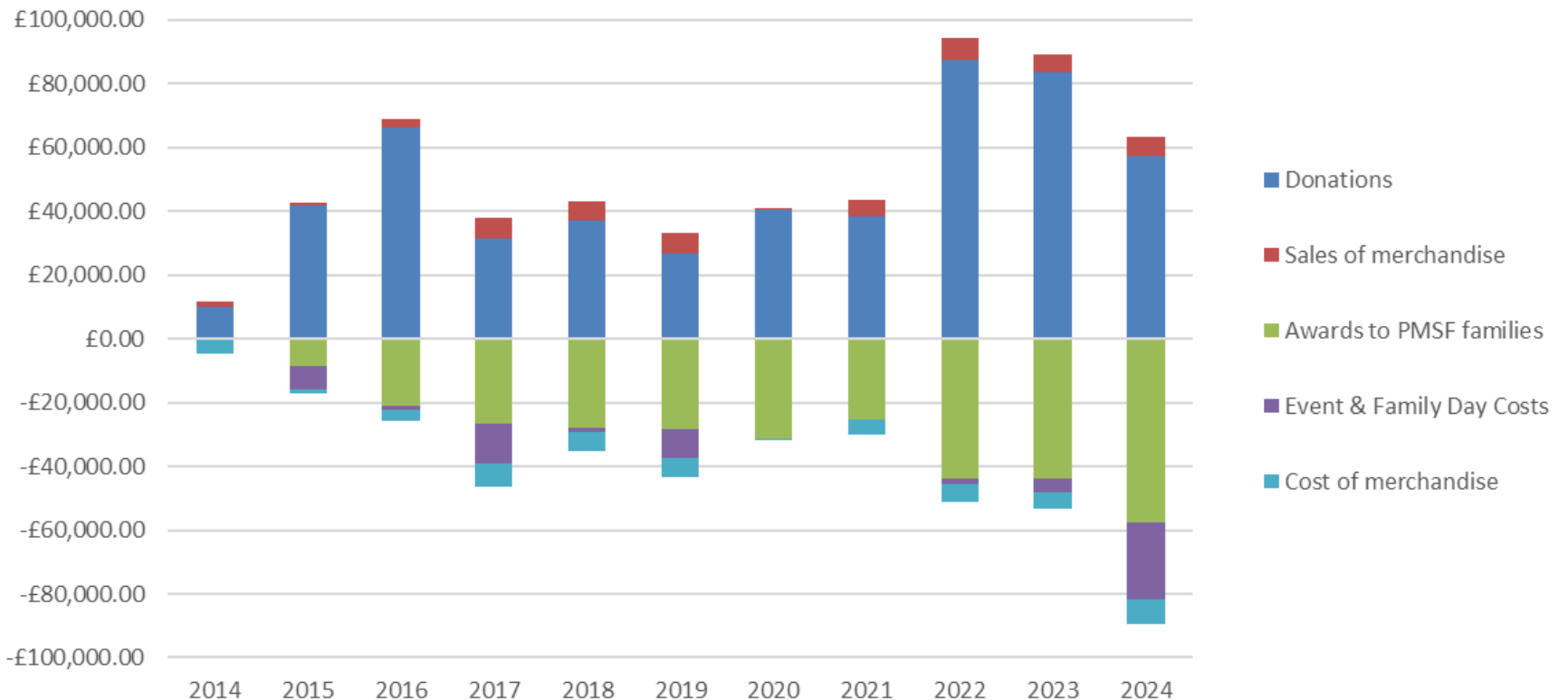
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Phelan-McDermid Syndrome Foundation UK

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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

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales - Charity number 1157423

Accounts

PMSF UK ANNUAL REPORT & AGM MINUTES

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

#	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: <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"> 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



Phelan-McDermid Syndrome Foundation UK

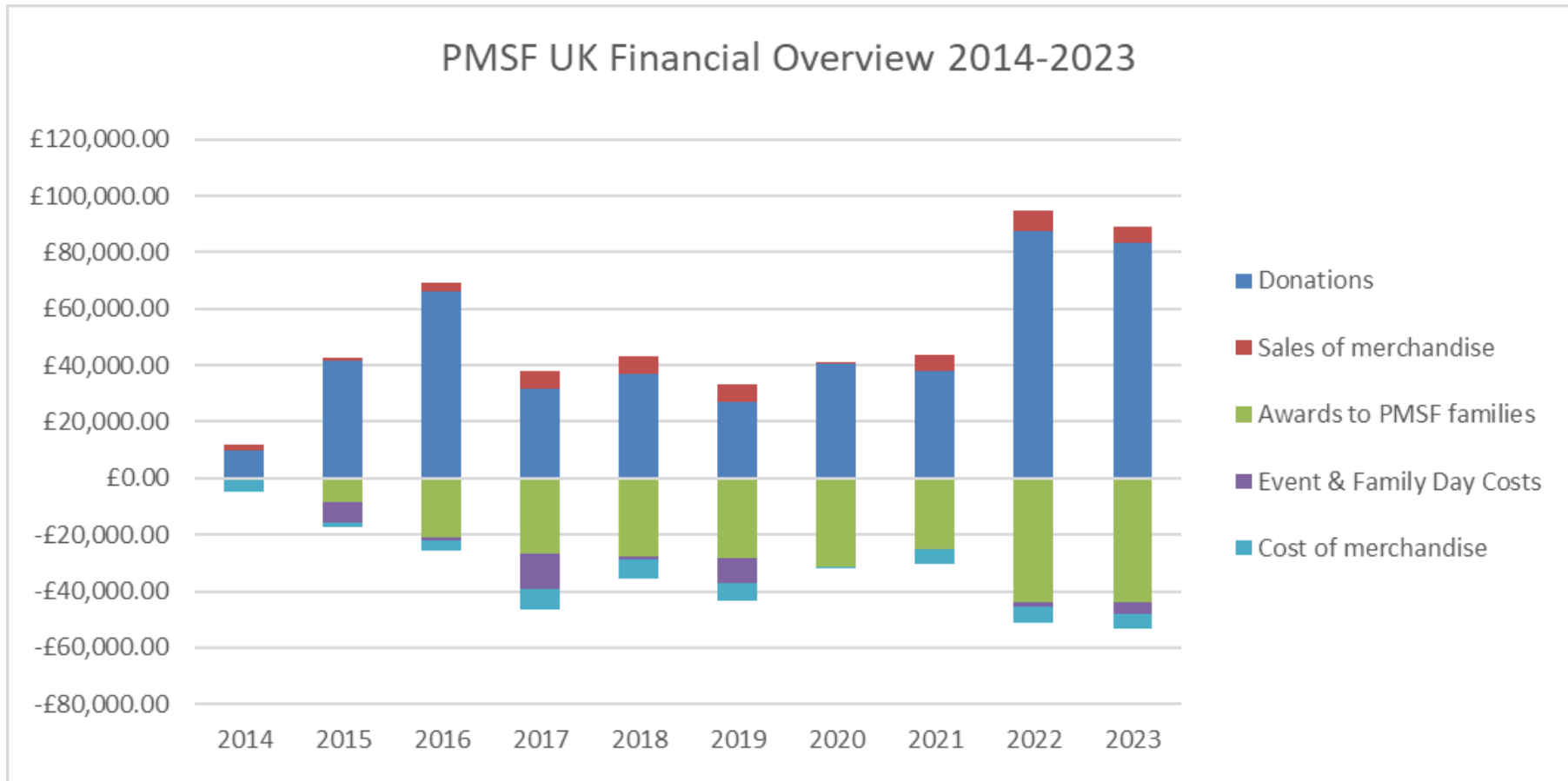
Section D	
Achievements and Performance – to 30-Sep-2023	<p>This is now our 9th full year as a charity, heading for our 10th anniversary in June 2024!</p> <p>Our community has grown to 360 people in the UK and Ireland with PMS now. As a reminder, it was just over 100 when we began as a registered charity 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



Phelan-McDermid Syndrome Foundation UK

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

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<i>PayPal</i>	£38.25	£1,260.05
<i>Benevity</i>	£0.00	£0.00
<i>EasyFundraising</i>	£74.79	£65.16
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Purchase of printed leaflets	£0.00	£0.00
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Agenda Item 4: 2022-23 Donations Summary



Phelan-McDermid Syndrome Foundation UK

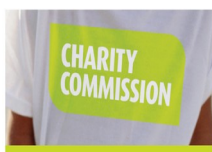
- Total donations of **£83,464.76** – from the following sources:
 - **£18,456 raised via JustGiving** consisting of **731 individual donations** made via the platform during the financial year
 - **£63,787 received as direct donations** (including a very generous legacy donation)
 - **£1,222 via other 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



Phelan-McDermid Syndrome Foundation UK

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
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CC16a

Receipts and payments accounts

For the period from	1-Oct-22	To	30-Sep-23
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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 £	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
B2 Other monetary assets	Details	to nearest £	to nearest £	to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	PMSF merchandise stock value, all items	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	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:

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales - Charity number 1157423

Accounts

PMSF UK ANNUAL REPORT & AGM MINUTES

AGM Held, Sun 15th January 2023, 14:30-15:30 via Zoom

#	Agenda Item	Presenter	Notes
1	Welcome / Introductions	Penny	<ul style="list-style-type: none"> Attendees were – Penny Bradley (T) (Chair), Alison Turner (T), Giles Bradley (T), Lynda White (T), Natalie James (T), Sarah Bickerstaffe (T) 6 trustees, shown as (T) above (min 2 required)
2	Regional Membership Status	Lynda / Alison	<ul style="list-style-type: none"> Now 320 region 6 members in UK/Ireland (as of Fri 6/1/23) (was 292 at last AGM in Nov 2021)
3	List of achievements in 2022	Giles	<ul style="list-style-type: none"> Summary of 2022 achievements approved and will be shared with the PMSF UK communication Photo highlights of the last PMSF UK year discussed
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> Draft accounts presented for review and agreed Will be presented for Independent Examination and then submitted to Charity Commission before the deadline of July 2023.
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 	All	<ul style="list-style-type: none"> Agreed. See separate slide 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)
6	Any other business	Penny to chair	
7	Closing	Penny	

Key Achievements and Performance Highlights – for the year to 30th September 2022

This is now our **8th 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



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



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

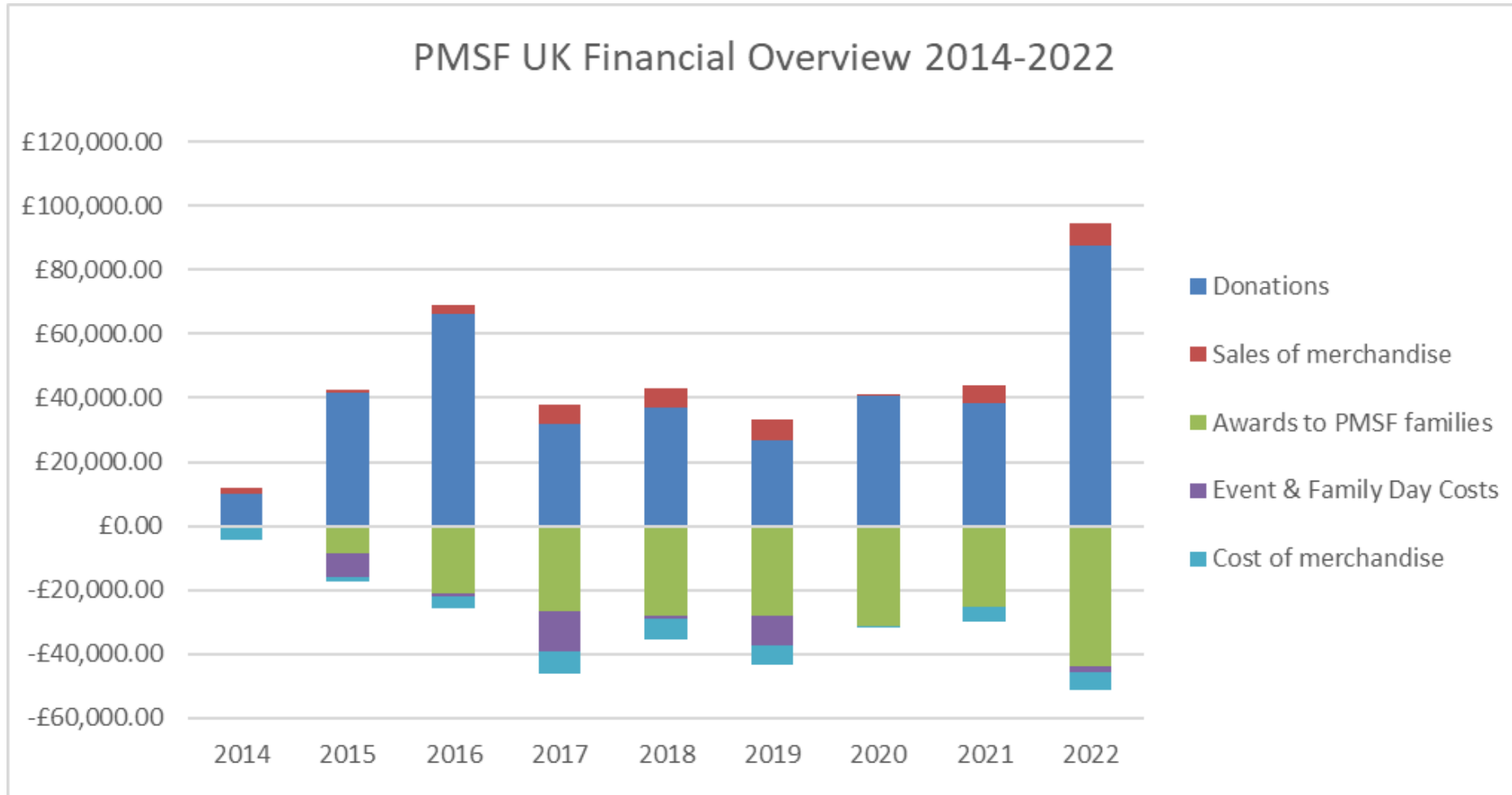


Agenda Item 3: A few highlights of our PMSF UK year



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
Cash		
Opening cash balance	£37,863.12	£27,459.32
Closing cash balance [bank & PayPal]	£71,842.83	£37,863.12
Receipts	£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
Payments	-£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



Phelan-McDermid Syndrome Foundation UK

- 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



Phelan-McDermid Syndrome Foundation UK

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">• For noting: Renewal of 3 year Trustee term (until 2025) for Lynda• For completeness, 6 trustees remain: Alison, Giles, Lynda, Natalie, Penny, Sarah.
c. Review of Charity Policies	<ul style="list-style-type: none">• No change to the charity's Policies
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)• Hold further regional gatherings in 2023 (as we did in 2022)• 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)

Agenda Items 6 & 7

#	Agenda Item	Presenter	Notes
1	Welcome / Introductions	Penny	<ul style="list-style-type: none"> Confirmation of trustee attendance (min 2 required)
2	Regional Membership Status	Lynda / Alison	<ul style="list-style-type: none"> Now 292 region 6 members in UK/Ireland (as of Tue 26/10/21) (was 281 at last AGM in Nov 2020)
3	List of achievements in 2022	Giles	<ul style="list-style-type: none"> Summary of 2021 achievements noted Recognition in appreciation of PMSF UK Awards noted
4	Review and approval of accounts	Giles	<ul style="list-style-type: none"> Draft accounts presented for review Subject to agreement, will be presented for Independent Examination and then submitted to Charity Commission before the deadline of July 2022.
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"> See separate slide
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 £
A1 Receipts				
Donations	87,489	-	-	87,489
Merchandise Sales	7,050	-	-	7,050
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
	-	-	-	-
Sub total (Gross income for AR)	94,538	-	-	94,538
A2 Asset and investment sales, (see table).				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-
Total receipts	94,538	-	-	94,538
A3 Payments				
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
	-	-	-	-
Sub total	60,559	-	-	60,559
A4 Asset and investment purchases, (see table)				
	-	-	-	-
	-	-	-	-
Sub total	-	-	-	-
Total payments	60,559	-	-	60,559
Net of receipts/(payments)	33,980	-	-	33,980
A5 Transfers between funds	-	-	-	-
A6 Cash funds last year end	37,863	-	-	37,863
Cash funds this year end	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 £
B1 Cash funds	Cash in bank / PayPal	71,843	-
		-	-
		-	-
	Total cash funds	71,843	-
	(agree balances with receipts and payments account(s))	OK	OK

	Details	Unrestricted funds to nearest £	Restricted funds to nearest £
B2 Other monetary assets		-	-
		-	-
		-	-
		-	-
		-	-
		-	-

	Details	Fund to which asset belongs	Cost (optional)
B3 Investment assets			-
			-
			-
			-
			-

	Details	Fund to which asset belongs	Cost (optional)
B4 Assets retained for the charity's own use	PMSF merchandise stock value, all items	Unrestricted	-
			-
			-
			-
			-
			-
			-
			-
			-

	Details	Fund to which liability relates	Amount due (optional)
B5 Liabilities			-
			-
			-
			-
			-

Signed by one or two trustees on behalf of all the trustees

Signature	Print Name
	Giles Bradley

CC16a

Last year
to the nearest £

38,219
5,531
-
-
-
-
-
-
43,749

-
-
-

43,749

25,376
-
-
-
-
530
4,738
2,702
-
33,346

-
-
-

33,346

10,404
-
27,459
37,863



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

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales - Charity number 1157423

Accounts

PMSF UK AGM MINUTES & ANNUAL REPORT

Sat 13th Nov 2021, 10:00am

Virtual meeting (*Zoom details provided to attendees*)

AGM Agenda and Minutes



Phelan-McDermid Syndrome Foundation UK

#	Agenda Item	Summary outcomes
1	Welcome / Introductions	<ul style="list-style-type: none"> Attendees were – Penny Bradley (T) (Chair), Alison Turner (T), Giles Bradley (T), Lynda White (T), Sarah Bickerstaffe, Kat Pond, Sylvia Millership 4 trustees, shown as (T) above, in attendance
2	Regional Membership Status	<ul style="list-style-type: none"> Now 292 region 6 members in UK/Ireland (as of Tue 26/10/21) (was 281 at last AGM in Nov 2020). Smaller increase than recent years – possibly fewer diagnoses / registrations during the pandemic?
3	List of achievements in 2021	<ul style="list-style-type: none"> See pages 3-4: Achievements per Annual Report reviewed – to be circulated to the PMSF UK community. Examples of appreciation from families receiving awards included on pages 4. Content from both pages to be added to the PMSF UK website.
4	Review and approval of accounts	<ul style="list-style-type: none"> See pages 5-7: Financial highlights reviewed. Accounts agreed for external independent opinion and subsequent submission to the Charity Commission
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 	<ul style="list-style-type: none"> See page 8
6	Any other business	<ul style="list-style-type: none"> Discussed Closed UK/Ireland Facebook group for families. In future, families moving to the UK will not be added to the closed Facebook Group until they have moved. No action to be taken for those outside the UK already added. Admins to reflect this in the group's policy. Plans to be created for wider awareness-building via the Shine Green initiative in the UK in 2022, after the success of lighting up King's College Cambridge in 2021. Discussed potential charity patron, if suitable profile-raising candidate can be identified Discussed benefit of having a UK-based medical practitioner involved with the PMSF UK community, and some follow-up items to seek support for this.
7	Closing	<ul style="list-style-type: none"> Attendees and supporters thanked for their contributions to another successful year for PMSF UK

Section D	
Achievements and Performance – to 30-Sep-2021	<p>This is now our 7th full year as a charity!</p> <p>Our community has grown to almost 300 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">• We have continued to prioritise making financial awards to families in the UK and Ireland. We made awards three times in each calendar year – and the end of September, January and May. In this financial year, we have awarded over £25,000 – to over 60 families from across our community. Almost 140 of our families have received awards since we began the awards initiative.• Our community has made fantastic efforts to fundraise for PMSF UK. We have, in particular, had more JustGiving pages and more donations via that channel than ever before. Overall donations continue to be very strong – which has continued already into the current financial year thanks to some significant fundraisers in October 2020.• Our website continues to be an important resource and to support awareness building – with over 5,000 views (13,000 page views) in the last 12 months.• Our Facebook following continues to grow steadily (542 followers, and specific postings sometimes reaching many thousands). This year, we are now also present on Twitter and Instagram.• We have re-started face-to-face meet-ups now, with a North region event held at Blackpool Zoo in October 2021• We have continued to raise funds and awareness through the sale of merchandise (seasonal cards and tops, face masks, also a bulk order this year of Phelan Lucky merchandise)

Agenda Item 3: Just some of the families' appreciation for awards in 2021...

Thank you!

Thank you so much for your support.

The help I have received so far has been invaluable to my little girl. We are extremely grateful.

Thank you so very much!

Amazing, thank you.

Thank you to all at PMSF UK!

Oh, that's fantastic news!

We are very grateful, thank you.

Thank you for your continuous support.

Thank you so much for the kind award.

Thank you so much for the award. It couldn't have come at a better time!

That's so lovely, thank you so much.

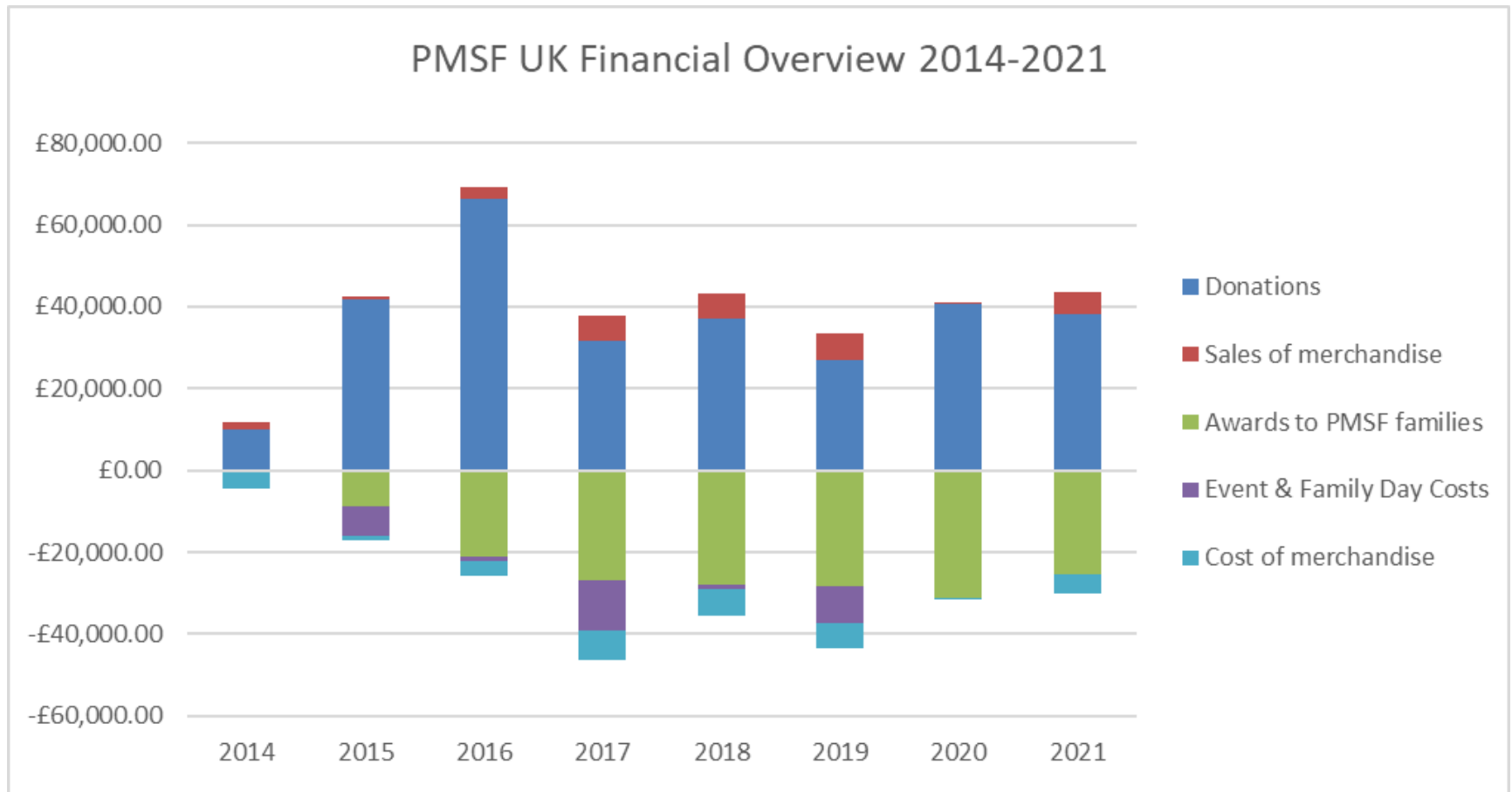
Thank you very much. Much appreciated and will make a huge difference to our forthcoming holiday!

Wow! Thank you so much, you have made my day!

Great news!

Agenda Item 4: Financial Highlights for 2020-21

- Continued consistent fundraising activity has allowed us to maintain a high level of financial awards to UK & Ireland families
- We will plan to hold a full UK/I Family Day in 2023 to remain in alternate years with the Global Conference



Agenda Item 4: Financial Results Detail

Will be submitted for Independent Examination and then to Charity Commission



Phelan-McDermid Syndrome Foundation UK

- **Healthy cash balance** at end of Sep 2021 (in readiness to support latest round of Awards and 2022 plans)
- **Donations continue at consistently strong levels.** 2021 has been the **best year of fundraising to-date via JustGiving** – reflecting the fundraising activity undertaken across our community.
- **Awards to families** has remained strong and has included **over 60 families** in the last year.
- Merchandise costs and sales, and expenses, reflect the **bulk purchase and distribution of Phelan Lucky merchandise** (to minimise UK supporters' shipping costs)
- **No committed out-goings** (no taxes, investments, property costs or employees)
- **Other Expenses** reflects costs of admin support, new banner for use at events, purchase of Outstanding Contribution Awards and Membership subscriptions (e.g. Genetic Alliance)

	This Year (2021) 1-Oct-20 to 30-Sep-21	2020 1-Oct-19 to 30-Sep-20
Cash		
Opening cash balance	£27,459.32	£22,126.53
Closing cash balance [bank & PayPal]	£37,863.12	£27,459.32
Receipts	£43,749.49	£41,137.72
Donations	£38,218.75	£40,745.85
<i>Restricted funds (1)</i>		
<i>Direct (2)</i>	£9,847.49	£17,191.03
<i>JustGiving</i>	£25,988.60	£19,044.72
<i>VirginGiving</i>	£0.00	£440.90
<i>FaceBook</i>	£1,422.07	£3,701.23
<i>Amazon</i>	£604.79	£214.65
<i>PayPal</i>	£314.16	£62.49
<i>Benevity</i>	£0.00	
<i>EasyFundraising</i>	£41.64	£90.83
Sales of merchandise (3)	£5,530.74	£391.87
<i>Sales of merchandise (Bank credits)</i>	£4,083.20	£0.00
<i>Sales of merchandise (PayPal)</i>	£1,447.54	£391.87
Payments	-£33,345.69	-£35,804.93
Awards to PMSF families	-£25,375.71	-£31,282.89
<i>Awards Programme (excl. Travel)</i>	-£25,375.71	-£31,282.89
<i>Travel awards</i>		
Research Awards (to US Foundation)	£0.00	-£1,250.00
Donation to PMSF (US Foundation)	£0.00	-£800.41
Website costs	£0.00	
Event costs (incl. Family Days)	£0.00	
Purchase of Charity Event Places	-£530.00	-£700.00
Purchase of merchandise	-£4,737.59	-£306.00
Purchase of printed leaflets	£0.00	
Postal expenses	-£505.13	-£200.00
JustGiving & Virgin costs	-£561.60	-£244.80
Other expenses (4)	-£1,635.66	-£1,020.83

Agenda Item 4: 2020-21 Donations Summary



Phelan-McDermid Syndrome Foundation UK

- Total donations of £38,219 – from the following sources:
 - £25,989 raised via JustGiving (the most we have ever raised via JustGiving)
 - £9,847 received as direct donations
 - £2,383 via other platforms (Virgin, Facebook, Amazon, PayPal, Easyfundraising)
- **We appreciate every donation to PMSF UK. - Thank you to all of our supporters**
- We would like to recognise a number of significant fundraising achievements and donations from 2020-2021.
- We hope that many of our community can be inspired to continue this great work in 2022!
 - ✓ Stuart and Helen Leighton
 - ✓ Emma and Charlotte Lacey's 100km challenge
 - ✓ Sammy Coomber
 - ✓ Bryony Blackburn Run
 - ✓ Holly Lodge Christmas Lights (12 Hillway Family)
 - ✓ Dale Rees Run
 - ✓ Lucy Atherton Cycling
 - ✓ Brian Sneddon Ben Nevis Climb
 - ✓ Jay Jaffa Triathlon
 - ✓ Natalie James, Lisa Meadows & Rachel James Run and Race Night
 - ✓ Claire Winstone Run
 - ✓ Amanda Grosvenor Channel Swim
 - ✓ James Picker & Mark Selves Running
 - ✓ All of our 'Run Like a Hero' fundraisers

Agenda Item 5: Items for agreement



Phelan-McDermid Syndrome Foundation UK

Item	Summary outcome
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 terms (until 2024) for Penny (continuing as Chair) and Natalie• For noting: Sarah Bickerstaffe confirmed as a new Trustee, bringing the total number of Trustees to 6• For completeness, 6 trustees will now be: Penny, Alison, Lynda, Natalie, Giles, Sarah.
c. Review of Charity Policies	<ul style="list-style-type: none">• No change to the charity's Policies
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)• Updated and re-hosted website to be re-launched• First regional gathering arranged in 2021 in North (Blackpool Zoo, October 2021). Other regional meet-ups to be planned and funded in 2022.• No UK-wide Family Day planned for 2022 now – To remain in alternate years from global conference, so will be arranged for 2023.



Phelan McDermid Syndrome UK 1157423

CC16a

Receipts and payments accounts
 For the period from 01-Oct-20 To 30-Sep-21

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	38,219	-	-	38,219	40,746
Merchandise Sales	5,531	-	-	5,531	392
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	43,749	-	-	43,749	41,138
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	43,749	-	-	43,749	41,138
A3 Payments					
Awards to Families	25,376	-	-	25,376	31,283
Research Awards	-	-	-	-	1,250
US Donation	-	-	-	-	800
Website costs	-	-	-	-	-
Events	-	-	-	-	-
Charity Event Places Purchase	530	-	-	530	700
Merchandise Purchase	4,738	-	-	4,738	306
Other	2,702	-	-	2,702	1,466
	-	-	-	-	-
Sub total	33,346	-	-	33,346	35,805
A4 Asset and investment purchases. (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	33,346	-	-	33,346	35,805
Net of receipts/(payments)	10,404	-	-	10,404	5,333
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	27,459	-	-	27,459	22,127
Cash funds this year end	37,863	-	-	37,863	27,459

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	37,863	-	-
		-	-	-
		-	-	-
	Total cash funds	37,863	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	PMSF merchandise stock value, all items	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	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		

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 2021.

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: 4 June 2022

PHELAN-MCDERMID SYNDROME FOUNDATION UK

England & Wales - Charity number 1157423

Accounts

PMSF UK AGM MINUTES & ANNUAL REPORT

Meeting held on Sun 15th Nov 2020, 10:00am via Zoom

AGM Agenda and Minutes



Phelan-McDermid Syndrome Foundation UK

#	Agenda Item	Summary outcomes
1	Welcome / Introductions	<ul style="list-style-type: none"> Attendees were – Penny Bradley (T) (Chair), Alison Turner (T), Giles Bradley (T), Lynda White (T), Natalie James (T), Sarah Bickerstaffe, Victoria Feddersen, Kat Pond, Sylvia Millership 5 trustees, shown as (T) above, in attendance
2	Regional Membership Status	<ul style="list-style-type: none"> Now 281 region 6 members in UK/Ireland (as of Fri 13/11) (was 244 at last AGM in Nov 2019)
3.1	List of achievements in 2020	<ul style="list-style-type: none"> See page 3: Achievements per Annual Report reviewed – to be circulated to the PMSF UK community. Examples of appreciation from families receiving awards included on pages 4-5.
3.2	Plans for 2020-2021	<ul style="list-style-type: none"> See page 3: Plans confirmed per Annual Report
4	Review and approval of accounts	<ul style="list-style-type: none"> See pages 6-8: Accounts agreed for external independent opinion and subsequent submission to the Charity Commission
5	Presented for agreement: <ul style="list-style-type: none"> Confirmation of Charity Objectives Confirmation of trustees Review of Charity Policies 	<ul style="list-style-type: none"> New 3-year term as Trustees confirmed for Alison Turner and Giles Bradley. Confirmation that limit to permitted number of Trustee terms to be removed. No other changes to objectives or policies
6	Any other business	<ul style="list-style-type: none"> Participation by 139 UK runners in Run Like a Hero event in October 2020 UK/I Family Day to be planned for 2022. Will review pandemic situation and continued rotation to avoid taking place in the same year as the Global Conference Regional Family Days to be held in 2021 if circumstances allow PMSF UK to complete registration with Virtual Runner (per Kat Pond nomination) Reminder via FB and email to UK/I families to use Amazon Smile and Easyfundraising to raise funds for PMSF UK Follow-up with Kyle's Angels to take place separately Next UK/I Regional Rep meeting to be held via Zoom

Agenda Item 3: Key achievements for 2019-2020 and plans for 2021

Annual Report to Charity Commission – Section D

Section D	
<p>Achievements and Performance – to 30-Sep-2020</p>	<p>In our 6th full year as a charity, we passed a milestone of over £0.25m in donations since we started. Our community has grown to 281 people with PMS now (was just over 100 when we began in 2014). Highlights for this financial year include:</p> <ul style="list-style-type: none"> • Record levels of financial Awards to UK/I families – over £31,000 in the year to 30-Sept 2020 • This includes prioritizing financial support for people with PMS during the Covid-19 pandemic through two sets of ‘Covid-19 awards’ in April and July 2020 where we awarded in total approx. £12,000 through 120 awards • Continued to make our regular awards at the end of September 2019, January 2020 and May 2020. • No regional gatherings, due to the pandemic – so will plan to support meet-ups next year / as soon as circumstances allow • Despite the pandemic’s impact, our financial donations were higher than any of the previous 3 years. Total donations were just under £41,000, incl. a £5,000 grant from Genetic Disorders UK to help fund our 2019 UK/I Family Day. • Raised funds and awareness again in 2019-2020 through the sale of Seasonal Cards. • Provided donations of £2,000 to PMSF and to PMSF Research (co-ordinated by the Global Foundation) • Continued to maintain the PMSF UK website as a key source of information for families and supporters. • Continued social media presence through Facebook (448 page likes / followers) • Continued to support UK-based EU AIMS research initiative
<p>Plans for 2020-2021</p>	<ul style="list-style-type: none"> • At year-end, we have a healthy cash balance – so that our awards programme can continue in 2021 • We will resume family days (likely regional in 2021, if circumstances permit) and will plan for a next UK-wide meet-up now 2022.

Agenda Item 3: Feedback from families on PMSF UK Awards

This is lovely news.
Thank you to the Trustees.
Very kind of you.

We are very grateful. Thank you Trustees!

Great news and will greatly benefit us.

Thank you all at PMSF UK. It is very much appreciated!

Thank you for the help you are giving us. We really do appreciate it.

Very touching that we receive the opportunity to apply for awards from our PMSF UK family.

Thank you. The smiles will not leave our faces all week!

Oh wow! Thank you so much. We're over the moon!

Thank you so much for this award! I'm so happy to hear this awesome news!

I would like to say a big thank you for being able to award us the funding this time round.

Thank you to all the Trustees. You really do not realise how much this means to us!

Agenda Item 3: Feedback from families on PMSF UK Covid Awards

The award is much appreciated in these mad circumstances

Thank you soooo much!

Thank you very much. It's much appreciated

Lovely surprise

I'm so pleased to hear the wonderful news. Thank you so so much!

Thank you so much. The award will make a huge difference.

Truly amazed at the support I continue to receive. Thank you.

I'm not even sure what to say. Thank you so much!! I was not expecting this.

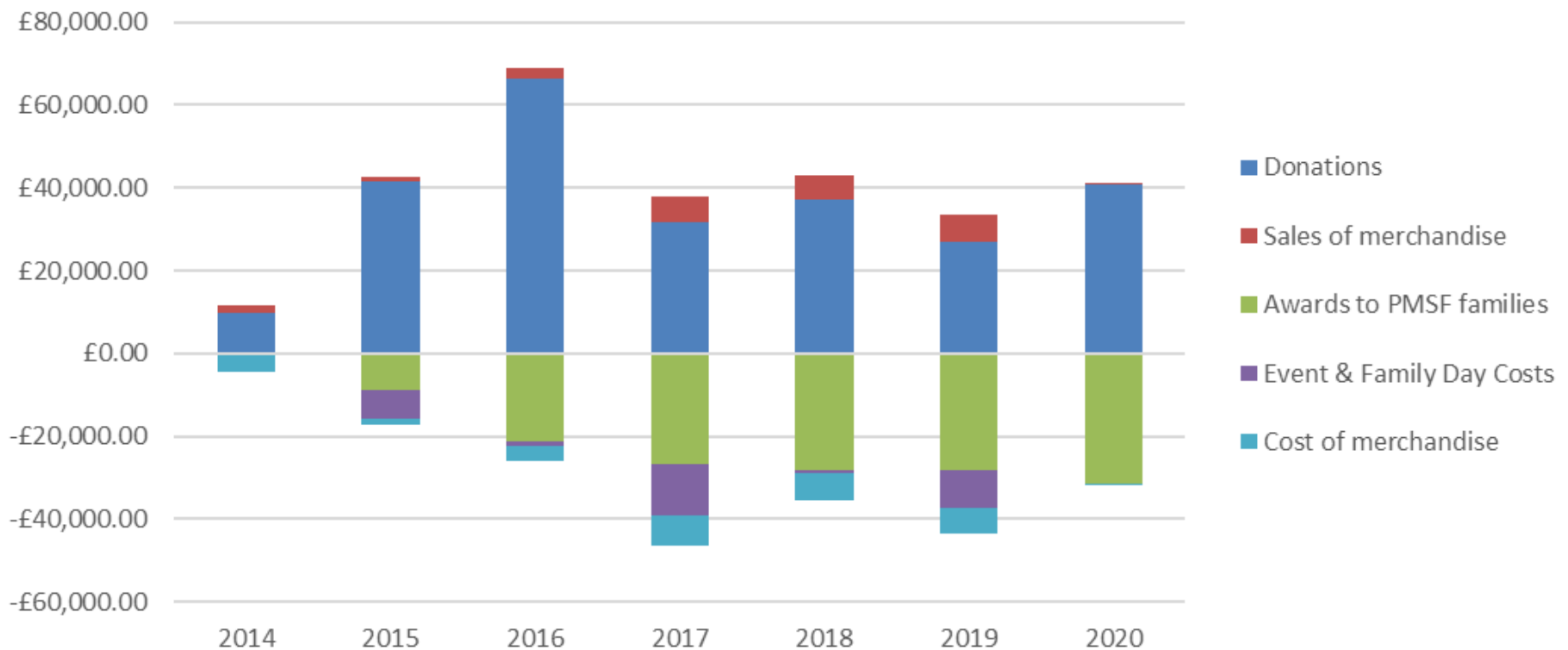
Thank you for the help you are giving us. We really do appreciate it.

That's fab news. Thank you Trustees!

Agenda Item 4: Financial Highlights for 2020

- Fundraising / donations have actually been higher this year, despite Covid-19, than the previous 3 years
- Out-goings have focused on maximising awards to families
- We will plan to hold a full UK/I Family Day in 2022 to remain in alternate years with the Global Conference

PMSF UK Financial Overview 2014-2020



Agenda Item 4: Financial Results Detail

Annual Report to Charity Commission – Section E



Phelan-McDermid Syndrome Foundation UK

- Donations at a 4 year high – mainly on a direct basis or via JustGiving (see separate analysis of donations)
- Awards to families, incl. Covid-19 awards, the highest we have ever made
- Merchandise costs and sales, and expenses, reduced to reflect PL merchandise ordered directly by UK supporters rather than consolidated
- Healthy cash balance at end of Sep 2020 (in readiness to support latest round of Awards)
- We are run on a voluntary basis and have no committed out-goings (no taxes, investments, property costs or employees), so able to keep running during the pandemic

	This Year (2020) 1-Oct-19 to 30-Sep-20	2019 1-Oct-18 to 30-Sep-19
Cash		
Opening cash balance	£22,126.53	£40,545.30
Closing cash balance [bank & PayPal]	£27,459.32	£22,126.53
Receipts	£41,137.72	£33,356.44
Donations	£40,745.85	£26,875.21
<i>Restricted funds (1)</i>		
<i>Direct (2)</i>	£17,191.03	£8,798.43
<i>JustGiving</i>	£19,044.72	£12,747.17
<i>VirginGiving</i>	£440.90	£3,347.43
<i>FaceBook</i>	£3,701.23	£1,251.19
<i>Amazon</i>	£214.65	£33.65
<i>PayPal</i>	£62.49	£502.91
<i>Benevity</i>		£125.00
<i>EasyFundraising</i>	£90.83	£69.43
Sales of merchandise (3)	£391.87	£6,481.23
<i>Sales of merchandise (Bank credits)</i>	£0.00	£5,400.50
<i>Sales of merchandise (PayPal)</i>	£391.87	£1,080.73
Payments	-£35,804.93	-£51,775.21
Awards to PMSF families	-£31,282.89	-£28,249.77
<i>Awards Programme (excl. Travel)</i>	-£31,282.89	-£26,199.78
<i>Travel awards</i>		-£2,049.99
Research Awards (to US Foundation)	-£1,250.00	-£2,000.00
Donation to PMSF (US Foundation)	-£800.41	-£1,000.00
Website costs		
Event costs (incl. Family Days)		-£9,009.31
Purchase of Charity Event Places	-£700.00	-£956.00
Purchase of merchandise	-£306.00	-£6,211.76
Purchase of printed leaflets		-£1,178.00
Postal expenses	-£200.00	-£626.46
JustGiving & Virgin costs	-£244.80	-£532.80
Other expenses (4)	-£1,020.83	-£2,011.11

Agenda Item 4: 2020 Donations Summary



Phelan-McDermid Syndrome Foundation UK

- Total donations of £40,745.85 – from the following sources:
 - £19,044.72 raised via JustGiving
 - £17,191.03 raised from direct donations
 - £4,510.10 via other platforms (Virgin, Facebook, Amazon, PayPal, Easyfundraising)
- **We appreciate every donation to PMSF UK. - Thank you to all of our supporters**
- We would like to recognise a number of significant fundraising achievements and donations from 2019-2020 (up to 30-Sept-2020).
- We hope that many of our community can be inspired to continue this great work in 2021!
 - ✓ Genetic Disorders UK Grant (towards UK/I 2019 Family Day)
 - ✓ Stuart and Helen Leighton
 - ✓ Kirstie Griffiths Charity Ball & Barclays Bank Matched Funding
 - ✓ Annoushka Lingham's Marathon for Frankie
 - ✓ Sonia Carballo and Mike Healey Vitality Big Half
 - ✓ Georgie Child's birthday fundraiser
 - ✓ Jack Windross, Harry's Heroes and Cohort 16 for the Mad March Mare
 - ✓ James Picker's Way of the Roses Charity Cycle
 - ✓ Giles and Penny Bradley Royal Parks Half 2019
 - ✓ Yasmin Bennison's August month of 5kms
 - ✓ Kaitlyn Atherton's haircut
 - ✓ Emma and Charlotte Lacey's 100km challenge



Phelan McDermid Syndrome UK 1157423

Receipts and payments accounts

CC16a

For the period from 01-Oct-19 To 30-Sep-20

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	40,746	-	-	40,746	26,875
Merchandise Sales	392	-	-	392	6,481
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	41,138	-	-	41,138	33,356
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	41,138	-	-	41,138	33,356
A3 Payments					
Awards to Families	31,283	-	-	31,283	28,250
Research Awards	1,250	-	-	1,250	2,000
US Donation	800	-	-	800	1,000
Website costs	-	-	-	-	-
Events	-	-	-	-	9,009
Charity Event Places Purchase	700	-	-	700	956
Merchandise Purchase	306	-	-	306	6,212
Other	1,466	-	-	1,466	4,348
	-	-	-	-	-
Sub total	35,805	-	-	35,805	51,775
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	35,805	-	-	35,805	51,775
Net of receipts/(payments)	5,333	-	-	5,333	- 18,419
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	22,127	-	-	22,127	40,545
Cash funds this year end	27,459	-	-	27,459	22,127

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	27,459	-	-
		-	-	-
		-	-	-
	Total cash funds	27,459	-	-
	(agree balances with receipts and payments account(s))	OK	OK	OK
B2 Other monetary assets	Details	Unrestricted funds to nearest £	Restricted funds to nearest £	Endowment funds to nearest £
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
		-	-	-
B3 Investment assets	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
			-	-
			-	-
			-	-
			-	-
			-	-
B4 Assets retained for the charity's own use	Details	Fund to which asset belongs	Cost (optional)	Current value (optional)
	PMSF merchandise stock value, all items	Unrestricted	-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
			-	-
B5 Liabilities	Details	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		

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 2020.

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: 7 Broadfields Avenue, London, N21 1AB

Date: 27 May 2021