

PMSF UK AGM MINUTES & ANNUAL REPORT

Sat 13th Nov 2021, 10:00am

Virtual meeting (*Zoom details provided to attendees*)

AGM Agenda and Minutes

#	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

Agenda Item 3: Key achievements for 2020-2021

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.

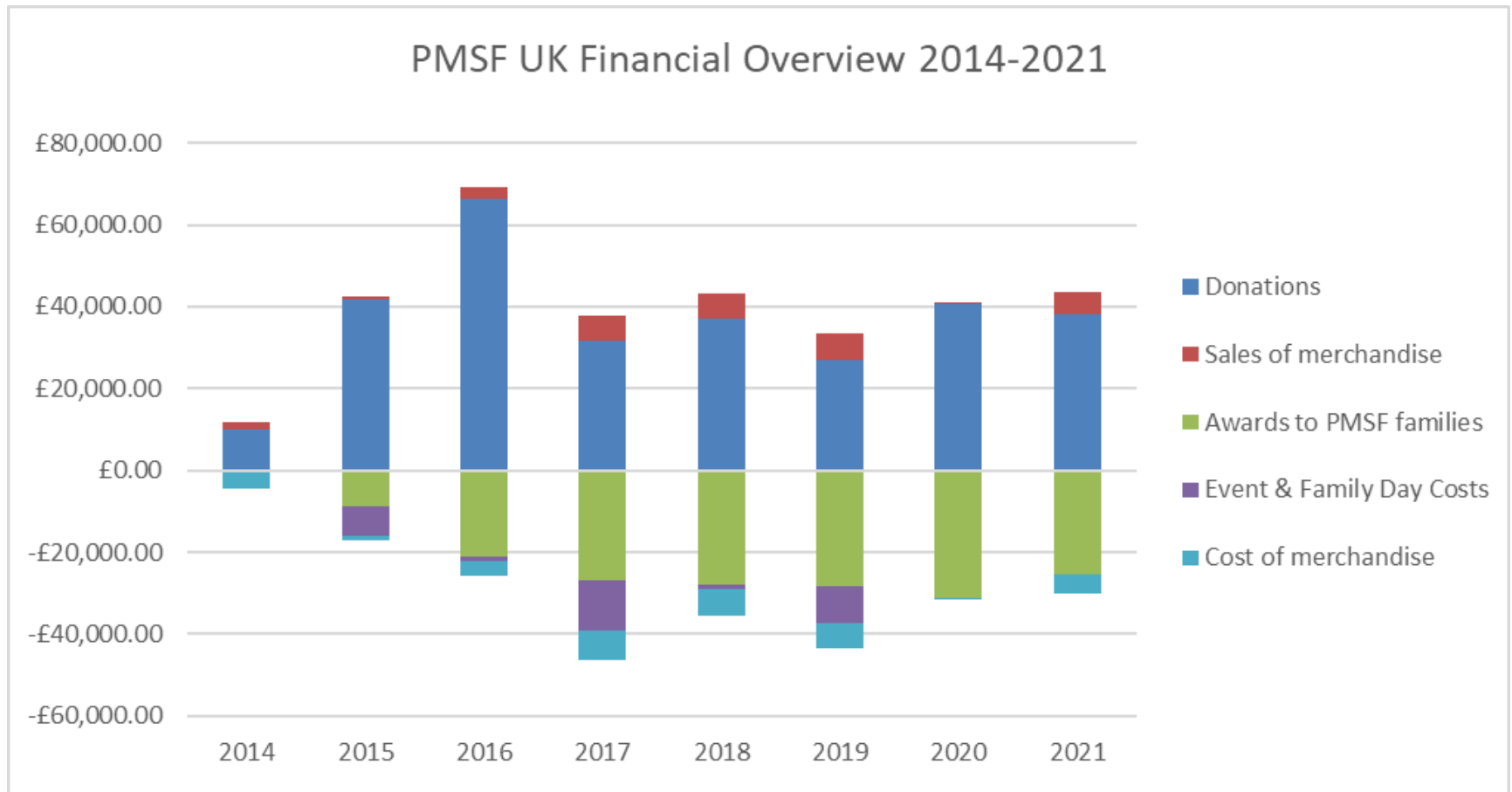
Thank you very much. Much appreciated and will make a huge difference to our forthcoming holiday!

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

- **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

- 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

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

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Receipts and payments accounts

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