

PMSF UK AGM MINUTES & ANNUAL REPORT

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

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), 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	
Achievements and Performance – to 30-Sep-2020	<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
Plans for 2020-2021	<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.

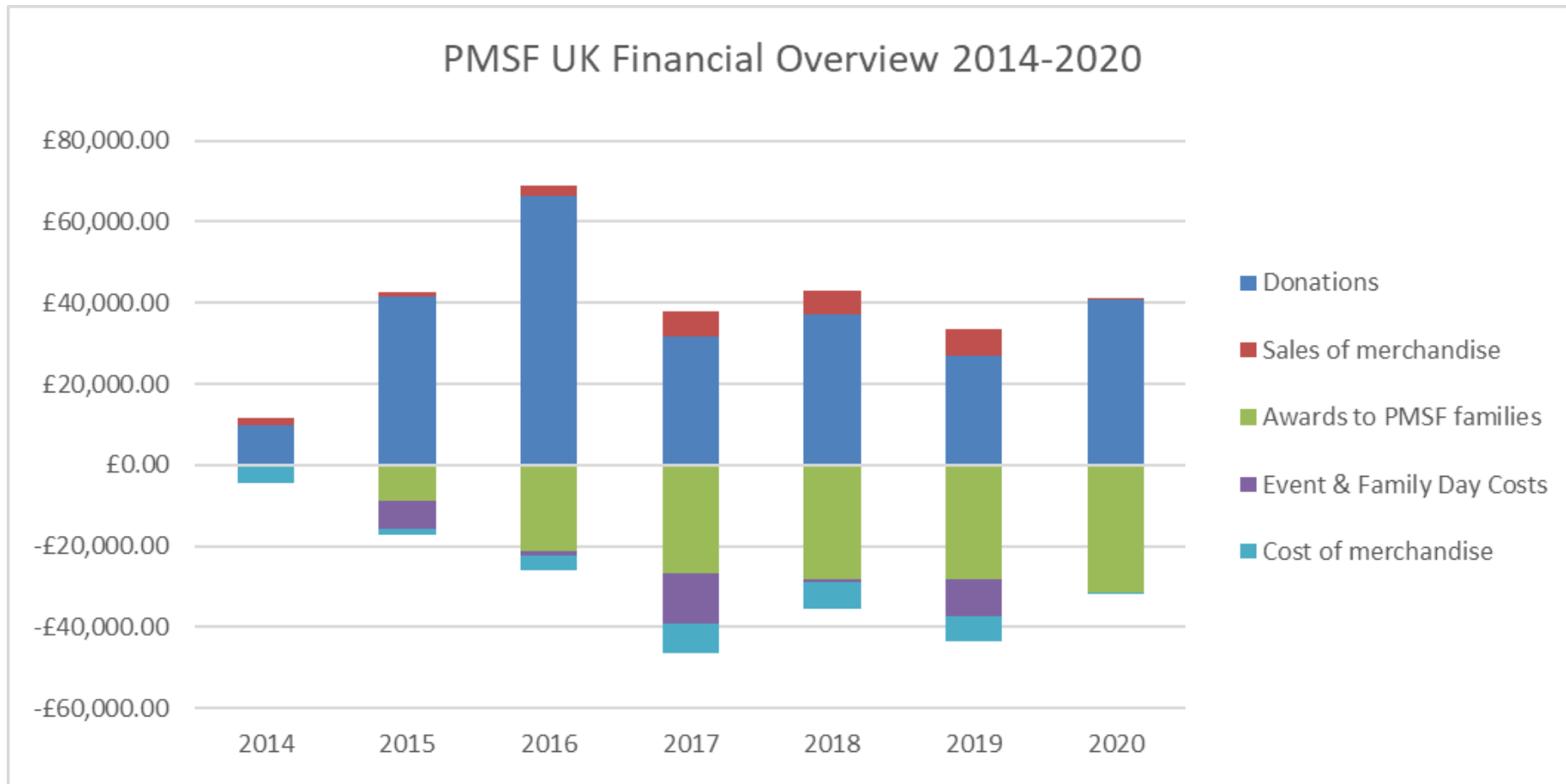
I'm not even sure what to say. Thank you so much!! I was not expecting this.

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



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

- 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

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Receipts and payments accounts

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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
		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 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