



PCPLD Network

Palliative Care for People with Learning Disabilities



TRUSTEE ANNUAL REPORT 2022-2023

Registered Charity No: 1171355

Twitter: @PCPLDNetwork

This Trustee Annual Report (TAR) covers the year from 1/4/2022 until 31/3/2023.

Current Trustees (as of early 2024)

The board of trustees consists of nine individuals who are mostly from healthcare (palliative care and learning disability) backgrounds

Professor Irene Tuffrey-Wijne

Dr Annie Stewart (secretary)

Dr Sarah Yardley

The following trustees joined us in October 2022

Dr Jo Elverson

Dr Valerie Potter

Louise Jenkins

Sarah Swindells

Sue Marsden -Chair -joined us in January 2023

Mick Howe (Treasurer)joined us in October 2023

Sadly our treasurer and founder trustee Steve Mitchell died in mid 2023 after a long illness.

He will be much missed by us all.

Carol Gray resigned from the trustee board in February 2023.

Gemma Allen(Chair 2019-January 2023) also resigned from the board having led PCPLD during the pandemic and was heavily involved in producing the many excellent webinars and podcasts.

We thank her for her enormous contribution and hard work for PCPLD. Gemma remains a member.

We advertised for a new Chair and following interviews, appointed Sue Marsden as our new Chair in January 2023. Sue is a Clinical Nurse Specialist & Community Team Leader in Palliative Care , Greenwich, London.

Current Specialist Advisory Group (SAG) (as of early 2024)

This group advises the trustees and are people with a wealth of experience, including lived experience, and knowledge about palliative care and learning disabilities.

Peter Allum (representing people with learning disabilities)
Pat Charlesworth (representing people with learning disabilities)
Jean Willson (retired social worker, representing family carers)
Louise Heatley (retired support worker, works in special educational needs)
Dr Kumar Cithambaran (Associate Professor in Intellectual disability, Dublin))
Catherine Wood (CEO of Mencap, Kirklees)
James Benfield (representing people with learning disabilities)
James Elsworthy (representing people with learning disabilities)
Dr Claud Regnard (Honorary Consultant in Palliative Medicine at St Oswalds' Hospice, Newcastle)
Phoebe Mooney Clinical Nurse Specialist in Learning Disability, St Christophers Hospice, London)) joined us in January 2023

Sian Mair Owen and Sharon Prowse left the group in 2022-2023 and we thank them both for their contributions and hard work for PCPLD.

PCPLD is supported by a part time website administrator, Anastasiya Stravolemova.

Membership

As of February 2024 we have 1549 members and membership remains free.

2022-2023 was a difficult year for us because of trustee illness so our planned Trustee away day in 2022 was postponed. We were also unable to hold a conference and we had fewer trustee meetings. It also highlighted the fact that our webinars and podcasts needed a huge amount of time and work devoted to them which was not possible.

Throughout the 2022-2023 year, individual trustees became involved in many projects concerning Learning Disability.

What Matters Most – this website and document for Health Care Professionals on advanced care planning and Cardio-Pulmonary Resuscitation in the community was produced by a group including Marie Curie and Royal College of GP Palliative Care lead amongst others. Gemma Allen and Sarah Yardley representing PCPLD were asked to comment on the information produced.

Medical Needs of adults with learning disability - new postgraduate qualification from Royal College of Physicians and Edgehill University. Section on palliative care written by Dr Valerie Potter.

Palliative Care Handbook - chapter on Learning Disability mentioning PCPLD written by Gemma Allen

Victoria and Stuart project - looking at co-designing a toolkit and resources for end of life care planning with people with learning disabilities within social care settings. The project is named after two of the people who inspired the research project Victoria Willson (1970-2013) and Stuart Hasler (1978-2020). Professor Irene Tuffrey Wijne is one of the two Principal Investigators and Gemma Allen and Sarah Swindells are two of the Co-Investigators. PCPLD is on an advisory group and is represented by Dr Annie Stewart.

A webinar in collaboration with PCPLD to officially launch the project was held on May 3rd 2022 - Jean Willson (a SAG member) shared the story of the life, dying and death of her daughter Victoria. There was a second collaborative webinar held on March 20th 2023 entitled ‘End of Life Care planning with people with Learning Disabilities’ - this was presented by Amanda Cresswell and Leon Jordan (both researchers with a learning disability) together with Irene Tuffrey Wijne.

Social Media -PCPLD X (formerly known as Twitter) account is managed by Dr Valerie Potter and Phoebe Mooney (SAG member)

Financial Report

(Year ending 31st March 2023)

The income for the year was £768 (£7,598 in 2021/22), mostly generated from Webinar proceeds. No grants were received in the year.

Expenses totalled £5,091 (£8,428 in 2021/22) resulting in a shortfall of income over expenditure of -£4,322 (-£829 shortfall in 2021/22). The major expense in the year was the cost of a website administrator. Costs associated with the planned new website will not be incurred until 2023/24

At the end of the year we carried forward £7,588 into 2023/24.

Trustee Away Day

This was held in February 2023. Topics covered included a review of our Business Plan written by our treasurer, Steve Mitchell, future conferences- topics/keynote speakers/place, Linda McEnhill award -continuing with award for 'Outstanding Care for an Individual' but changing the award for 'Innovative Practice' to 'Organisational Change'. Next award due in 2023 and to be announced in 2024.

Website

A major decision was taken at the away day by the trustees to commission a company to redesign and re-brand our website. A sub group was formed to oversee this and the expected launch of the website with the new logo will be in 2024.

Dr Annie Stewart, secretary of PCPLD
Mrs Sue Marsden, Chair of PCPLD

Palliative Care for People with Learning Disabilities
(PCPLD Network)

Charity No: 1171355

Accounts for the 12 months ending 31st March 2023

Trustees

S Marsden
J Elverson
L Jenkins
V Potter
S Swindells
S Mitchell
Dr A Stewart
Prof I Tuffrey-Wijne
Assoc Prof S Yardley

Bank

Lloyds Bank - Andover Branch

Independent Financial Examiner

Mrs A Day

PCPLD Network
Charity No: 1171355

Balance Sheet to 31st March 2023

	Mar-23		Mar-22	
	£	£	£	£
Fixed Assets		0		0
Current Assets				
Lloyds Bank	£6,798.73		£10,835.20	
Debtors	1 789.39	£7,588.12	1075.66	£11,910.86
Creditors		£0.00		£0.00
		£7,588.12		£11,910.86
Free Reserves		4588.12		11910.86
IT Reserve		3000.00		
		£7,588.12		£11,910.86

1

Refund re National Awards - refunded to PCPLD Credit Card

Signed:
PCPLD Trustee

S Marsden
S Marsden

Dated 30-4-23

PCPLD Trustee

S. Mitchell
S. Mitchell

Dated 26/4/23

Independent Financial Reviewer

I have reviewed the accounting records presented to me and found them to be adequate and the accounts are in accordance with records supplied. The accounts are for the 12 months ending the 31st March 2023

Independent Examiner

A Day

A. Day FCPA, CMAA



BS

PCPLD Network
Charity No: 1171355

Sources & Application of Funds 2022/2023

	2022/23		2021/22	
Income	£		£	
Webinar - 22/23	698.79	91%	337.83	
Donations - Others	65.00	8%	1205.06	
Amazon Smile	5.00	1%	6.63	
Conference 21		0%	5928.90	
L McEnhil Awards		0%	120.00	
	<u>£768.79</u>	100%	<u>£7,598.42</u>	100%
Expenditure				
Website Manager	3360.00	66%	7170.00	
Away Day 2023	1321.47	26%	0.00	
Zoom Sub	143.88	3%	143.88	
Business email	110.39	2%	105.66	
Webinar Exp's - Mar 23	93.79	2%	0.00	
Credit Card Fee	32.00	1%	64.00	
Leaving Gifts - Gemma	30.00	1%	0.00	
National Awards	0.00	0%	606.34	
Eventbright - Conference Fees	0.00	0%	508.90	
Webinar Expenses	0.00	0%	428.45	
Conference 21 Exp's	0.00	0%	177.65	
Double Click - Renew domain name	0.00	0%	30.00	
Misc	0.00	0%	11.34	
Lottery Community Fund -Accrual/Reverse	0.00	0%	-818.00	
	<u>£5,091.53</u>	100%	<u>£8,428.22</u>	
Excess Income over Expenditure	<u>-£4,322.74</u>		<u>-£829.80</u>	
B/fwd	£11,910.86		£12,740.66	
C/fwd	<u>£7,588.12</u>		<u>£11,910.86</u>	
Unrestricted Reserves	£4,588.12		£11,910.86	
Restricted Reserve	£3,000.00		£0.00	
	<u>£7,588.12</u>		<u>£11,910.86</u>	