

PALLIATIVE CARE FOR PEOPLE WITH LEARNING DISABILITIES NETWORK

England & Wales · Charity number 1171355

Details

Other names	PCPLD NETWORK
Status	Registered
Legal form	CIO
Registered	2017-01-27
Register	View on the Charity Commission register

Contact

Address 1 Greenbank Terrace
Hillside
South Brent
Devon
TQ10 9AX

Phone 01364 641547

Email info@pcpld.org

Website www.pcpld.com

Activities

Objects: THE OBJECT OF THE CIO IS, THE RELIEF AND ASSISTANCE OF PEOPLE WITH LEARNING DISABILITIES IN ANY PART OF THE WORLD DURING ILLNESS FOR WHICH PALLIATIVE CARE IS APPROPRIATE, OR WHO ARE EXPERIENCING THE DEATH OF SOMEONE CLOSE TO THEM, BY:1. RAISING AWARENESS OF THE PALLIATIVE CARE NEEDS OF PEOPLE WITH LEARNING DISABILITIES2. SHARING AND PROMOTING BEST PRACTICE3. ENHANCING COLLABORATION BETWEEN ALL PROFESSIONALS, CARERS AND PEOPLE WITH LEARNING DISABILITIES4. DOING OTHER LAWFUL THINGS AS NECESSARY FOR THE ACHIEVEMENT OF THESE OBJECTS.

Activities: Palliative Care for People with Learning Disabilities Network exists to raise awareness of the palliative care needs of people with learning disabilities, to share and promote best practice, and to enhance collaboration between all services providers, health care professionals, paid care staff, family carers, carers with a learning disability and people with a learning disability.

Classification

- **How:** Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** People With Disabilities

Geography

- Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,759	£614	-	-
2024-03-31	£1,485	£6,950	-	-
2023-03-31	£768	£5,091	-	-
2022-03-31	£7,598	£8,428	-	-
2021-03-31	£13,393	£10,482	-	-

Trustees

Name	Role	Appointed
Sue Marie Marsden	Chair	2023-02-28
Dr ANNIE ELIZABETH STEWART		2017-02-07
Dr Joanna Elverson		2022-10-03
Dr Valerie Anne Julia Potter		2022-10-03
JANE ELIZABETH NICKELS		2024-06-10
Louise Jenkins		2022-10-03
Michael Howe		2023-10-13
PHOEBE MOONEY		2024-03-17
SARAH SWINDELLS		2022-12-08

Accounts

PCPLD NETWORK

Charity Number 117355

TRUSTEE ANNUAL REPORT (2024-2025)

Through the 2024-2025 period we continued to focus on the development of our new website. Whilst it is now public, it remains a work in progress, as we learn about website management.

The investment in the new branding has enabled us to project the image of the PCPLD further and encouraged us to consider materials that Trustees and supporters can use to publicise the charity.

Following our decision last year that we were unable to run a conference due to the financial commitment, the charity has joined with Kingston University as academic partners this year – and this has offered us the opportunity to arrange a conference using university buildings and admin support. We look forward to this event in July 2025.

This collaboration with Kingston University will hopefully mean we able to run further conferences – with an aim to do this bi-annually.

This year has seen a significantly smaller financial outlay due to the decisions made last year regarding expenditure. We also received an unexpected £1000 donation and have received a small amount of income from “Easy fundraising” donations.

The PCPLD Network remains committed to supporting research projects into Palliative Care for people with Learning Disabilities, and following the successful launch of the Victoria and Stuart Project resources at a conference in July 2024, we now have several members of the charity involved in the focus groups and professional advisory group for the DAPPLE project. The DAPPLE project is a co-researched and co-produced project looking at developing effective service models for adult palliative and end of life care for people with a learning disability.

In September 2024, Irene Tuffrey-Wijne decided to step down from the Charity, and having agreed earlier in the year to not award the Linda McEnhill prize for 2023 – we then decided to retire the award as we felt that its aim – to promote and recognise Best Practice in EOLC for people with Learning Disabilities – had been achieved. Each year it has been harder and harder to find a winner, with complex EOLC for individuals now becoming more typical practice, and increasingly financial diversity across nominees which has made the playing field rather uneven.

We remain hugely grateful to Irene for her dedicated support to the PCPLD, and for her on going work in this field.

Phoebe Mooney – who joined us as a Trustee in 2023-2024 has now been nominated and accepted as joint Chair alongside Sue Marsden, and Jane Nickels also joined us a trustee. Jane is a Learning Disability Nurse with a specialism in Dementia.

Sue Marsden

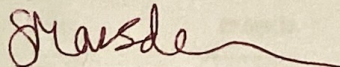
Chair PCPLD Network

January 2026

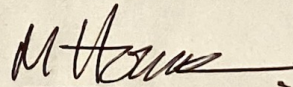
PCPLD Network
Charity No: 1171355
Balance Sheet as at 31st March 2025

	<u>31/03/2025</u>	<u>31/03/2024</u>
	£	£
CURRENT ASSETS		
Lloyds Bank Account	£3,161.84	£1,687.91
Credit Card Balance	£106.91	£435.11
	£3,268.75	£2,123.02
CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		
	£0.00	£0.00
NET CURRENT ASSETS	£3,268.75	£2,123.02
RESERVES		
IT Reserve	£0.00	£0.00
Free Reserve	£3,268.75	£2,123.02
	£3,268.75	£2,123.02

Signed:
PCPLD Trustee


Sue Marsden

PCPLD Trustee


Mick Howe

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 31/03/2025

Ness Mitchell

PCPLD Network
Charity No: 1171355
Source and Application of Funds
FOR THE PERIOD ENDED 31st March 2025

	2024/25		2023/24	
	£		£	
INCOME				
Webinar	50.01	3%	688.02	46%
Large Donation	1,000.00	57%		0%
Small Donations	87.75	5%	160.00	11%
Other	21.74	1%	137.16	9%
Kingston Uni	600.00	34%	500.00	34%
	<u>£1,759.50</u>	100%	<u>£1,485.18</u>	100%
EXPENDITURE				
Web manager	280.00	46%	3,080.00	44%
Website	-	0%	3,516.00	51%
Google	173.64	28%	110.40	2%
Zoom	155.88	25%	143.88	2%
misc	4.25	1%	100.00	1%
	<u>£613.77</u>	100%	<u>£6,950.28</u>	100%
Excess Income over Expenditure	<u>£1,145.73</u>		<u>-£5,465.10</u>	
B/fwd	<u>£2,123.02</u>		<u>£7,588.12</u>	
C/fwd	<u>£3,268.75</u>		<u>£2,123.02</u>	

Accounts

PCPLD NETWORK
Charity Number 1171355

TRUSTEE ANNUAL REPORT (2023-2024)

Our main achievement during this year was the creation of our new website www.pcpld.com which was launched quietly in 2024. This success was due to the committed ongoing work by the website sub-group - comprising trustees and a member of our Specialist Advisory Group. Back in 2022 a decision had been taken by the trustees to replace our old outdated website and employ a professional website designer.

Agency for Good is the company we have used to help us in our decision making - choosing new colours, a new logo and providing a new layout and deciding on particular content. We still need to amend the detail on the website and this remains an ongoing piece of work.

We had hoped to hold a face to face national conference in 2023/2024 but unfortunately we were unable to do this as we could not afford to underwrite a conference. This decision followed several unsuccessful grant applications including one to the National Lottery Community Fund.

Acknowledging our dwindling financial state also led us to the difficult decision of parting company with our website administrator. Anastasiya has worked for us in a part time capacity for many years and was the technological mastermind behind our extremely successful webinars and podcasts produced during the pandemic. We are and remain extremely grateful to Anastasiya for all that we achieved during her time with PCPLD.

We also discussed other ways of improving our financial situation beyond grant applications, namely direct appeals for donations,

fundraising webinars and the possibility of introducing a membership fee.

The Linda McEnhill award 2023 initially attracted only a small number of nominations so the closing date was extended to January 2024. In all we received only eight nominations and after much discussion by a judging panel consisting of trustees and members of our Specialist Advisory Group including two people with learning disability, a decision was made not to award a prize for 2023. We did not come to this decision lightly but in previous years we have had up to twenty nominations showcasing excellence with a team or a single individual. It was felt this was not the case in 2023 so we decided not to award. We are having ongoing discussions about the future direction of the award.

PCPLD Network was extremely proud to be associated with the Victoria and Stuart project which in mid 2024 has produced a toolkit for End of Life Care for people with Learning Disability. One of the principal researchers was Professor Irene Tuffrey-Wijne, one of our trustees and former chair of PCPLD Network. Among the researchers was another of our trustees, Sarah Swindells and one of our former chairs Gemma Allen. Focus groups involved people with learning disabilities, families, learning disability support staff, and healthcare professionals. The tool kit includes resources and approaches to support staff with end of life care planning with people with learning disabilities. Our network hosted all of the six webinars and all are available to view on You-tube.

Finally during 2023/2024 we welcomed two new trustees to our board. Mr Mick Howe ,our new finance officer and Miss Phoebe Mooney, a Clinical Nurse Specialist for people with learning disabilities at St Christopher's hospice, London.

Sue Marsden
Chair PCPLD Network
January 2025

PCPLD Network
Charity No: 1171355
Balance Sheet as at 31st March 2024

	<u>31/03/2024</u>	<u>31/03/2023</u>
	£	£
CURRENT ASSETS		
Lloyds Bank Account	£1,687.91	£6,798.73
Credit Card Balance	£435.11	£789.39
	£2,123.02	£7,588.12
CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR	£0.00	£0.00
NET CURRENT ASSETS	<u>£2,123.02</u>	<u>£7,588.12</u>
RESERVES		
IT Reserve	£0.00	£3,000.00
Free Reserve	£2,123.02	£4,588.12
	<u>£2,123.02</u>	<u>£7,588.12</u>

Signed:
PCPLD Trustee



Sue Marsden

PCPLD Trustee


Mick Howe

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 31/03/2024


Ness Mitchell

PCPLD Network
Charity No: 1171355
Source and Application of Funds
FOR THE PERIOD ENDED 31st March 2024

	2023/24		2022/23	
	£		£	
INCOME				
Webinar	688.02	46%	698.79	91%
Donations	160.00	11%	65.00	8%
Other	-		5.00	1%
Amazon	37.16	3%		0%
Marie Curie	100.00	7%		0%
Kingston Uni	500.00	34%		0%
	£1,485.18	100%	£768.79	100%
EXPENDITURE				
Web manager	3,080	44%	3,360.00	66%
Website	3,516	51%		0%
Google	110	2%		0%
Zoom	144	2%	143.88	3%
misc	100	1%		0%
Business Email		0%	110.39	2%
Webinar Expenses 2023		0%	93.79	2%
Credit Card Fee		0%	32.00	1%
Leaving Gifts		0%	30.00	1%
Away Day 2023		0%	1,321.47	26%
	£6,950.28	100%	£5,091.53	
Excess Income over Expenditure	-£5,465.10		-£4,322.74	
B/fwd	£7,588.12		£11,910.86	
C/fwd	£2,123.02		£7,588.12	
IT Reserve	£0.00		£3,000.00	
Free Reserve	£2,123.02		£4,588.12	

PALLIATIVE CARE FOR PEOPLE WITH LEARNING DISABILITIES NETWORK

England & Wales - Charity number 1171355

Accounts



PCPLD Network

Palliative Care for People with Learning Disabilities



TRUSTEE ANNUAL REPORT 2022-2023

Registered Charity No: 1171355

Twitter: [@PCPLDNetwork](https://twitter.com/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
		<u>£7,588.12</u>		<u>£11,910.86</u>
Free Reserves		4588.12		11910.86
IT Reserve		3000.00		
		<u>£7,588.12</u>		<u>£11,910.86</u>

1

Refund re National Awards - refunded to PCPLD Credit Card

 Signed:
PCPLD Trustee


S Marsden

Dated 30-4-23

PCPLD Trustee


S. Mitchell

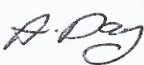
Dated 26/4/23

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, CMLIF



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	
Eventbrite - 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>	

PALLIATIVE CARE FOR PEOPLE WITH LEARNING DISABILITIES NETWORK

England & Wales - Charity number 1171355

Accounts



PCPLD Network

Palliative Care for People with Learning Disabilities



ANNUAL REPORT 2020-2021

Palliative Care for People with Learning Disabilities Network

Email: info@pcpld.org

Twitter:

Registered Charity No: 1171355

Website: www.pcpld.org

@PCPLDnetwork

Introduction

This year has been marked by the uncertainties, challenges and the devastating impact of the COVID-19 pandemic. It has affected our PCPLD Network community, our colleagues working in health and social sectors, people who are most clinically vulnerable and those who have felt lonely and isolated.

Whilst it was a privilege to take over from interim Chair, Professor Irene Tuffrey-Wijne in September 2020, it hasn't been the easiest of years to lead a small charity. We have seen a significant change in the way that we source our income, after the cancellation of our 2020 Conference. However, PCPLD Network responded by successful collaborations with individuals and organisations, developing and leading the way in online educational webinars that were delivered to thousands of health and social care professionals and family carers.

We navigated change, explored different ways to generate income and adapted to new ways of working. We passionately and loudly campaigned for people with learning

disabilities, including the voices of people with lived experience and highlighted blanket DNACPR decisions and COVID-19 vaccines, hitting the BBC News headlines with our friends from the GRASSroots group.

This was only possible due to the determination, time, reassurance and courage of the Board of Trustees and Specialist Advisory Group. The PCPLD community is quite something and the support of our members this year has gone above and beyond. Together, we are ensuring that people with learning disabilities live well until they die, with equitable palliative and end of life care, including bereavement support.

There is much to celebrate and continue to build on in the coming year and I am delighted to share our Annual Report 2020-21 on behalf of the Board of Trustees.



Gemma Allen
Chair of PCPLD Network
August 2021

Trustees and Specialist Advisory Group

The Board of Trustees consist of six individuals, mainly from health and social care backgrounds. We have met this year on zoom and communicated regularly via email. Trustees make the overall decisions for PCPLD Network and are supported by the Specialist Advisory Group.

PCPLD Trustees:

- Gemma Allen (Chair)
- Dr Annie Stewart (Secretary)
- Steve Mitchell (Treasurer)
- Dr Sarah Yardley
- Professor Irene Tuffrey-Wijne
- Carol Gray

As required by PCPLD Network constitution, Gemma Allen and Steve Mitchell will retire from office and stand for re-election at the next AGM on 16th September 2021.

We are extremely fortunate to have sixteen individuals with a wealth of experience and knowledge about palliative care and/or learning disability on our Specialist Advisory Group. Since September 2020, the Specialist Advisory Group have met twice on zoom as a group, in addition to smaller meetings for work task groups.

Current Specialist Advisory Group:

- Pat Charlesworth (representing people with learning disabilities)
- Peter Allum (representing people with learning disabilities)
- James Benfield (representing people with learning disabilities)
- James Elmsworth (representing people with learning disabilities)
- Dr Jo Elverson (Consultant in Palliative Medicine, St Oswald's Hospice)
- Dr Valerie Potter (Consultant in Palliative Medicine, St Bartholomew's Hospital)
- Louise Jenkins (Strategic Lead Nurse, Hertfordshire Community Learning Disability Nursing Service)
- Louise Heatley (Retired support worker. Works in special educational needs)
- Kumar Cithambaram (Lecturer at School of Nursing and Midwifery, Queen's University)
- Sharon Prowse (Senor Manager, Freeway Bristol)
- Catherine Wood (Chief Executive Office. Representing family carers)
- Sian Mair Owen (Independent advisor in autism, learning disabilities and inclusion. Representing family carers)
- Jean Wilson (Representing family carers)

Webinars and conferences

In September 2020, we took the plunge of hosting online education events, moving our conference online with support from PCPLD Network Website Manager, Anastasiya Stravolemova, and the IT team at Kingston and St Georges University. This event attracted an audience of 1,700 people and was later viewed 1,800 times on YouTube. Feedback suggested the need for PCPLD Network to host regular webinars, so we formed a small working group to organise and deliver regular webinars. The team behind these events are Professor Irene Tuffrey-Wijne, Gemma Allen and Anastasiya Stravolemova, with additional support from Louise Jenkins and Sharon Prowse.

8 online education events have been delivered by PCPLD Network, with over 9,000 people attending!

PCPLD Network usual face-to-face conference is our only source of income and therefore the decision to alter the format of the 2020 conference was not taken lightly by the Board of Trustees. However, inspired by our previous events, we decided to run a full day online conference on 16th September 2021. We have planned a phenomenal programme with keynote speakers including

Professor Mark Taubert, Dr Katherine Mannix, Dr Jo Elverson and David Harling. A call for abstracts received an inspiring response of papers submitted that have allocated space within the agenda. It's not too late to book a place for our Annual Conference and you can do so [here](#).

Planning online events is time consuming and we could not do it without the dedication of the planning team and speakers. I would like to express my personal gratitude to everyone involved or who has participated this last year.

'The PCPLD Network are pioneers in raising the voices of people with a learning disability and educating those who are supporting them. I am learning so much from their inclusive webinars and passion for people with a learning disability to be recognised for the worth and value they hold. They confront the injustice and discrimination faced by people with a learning disability at the end of their lives (and during) with power and patience. An incredible example of how to campaign, share best practice and truly advocate for learning disabilities.'

Podcasts

Another new experience for PCPLD Network is podcasting! Whilst this remains in its early stages you can hear our current available podcasts by visiting PCPLD Network Soundcloud account. Again, thank you to everyone who contributed time and effort into these podcasts.

Membership

Our last Annual Report announced that as of 21st August 2020, PCPLD Network had 320 registered members. I am delighted to say that this has increased over the last year and there are now 1763 members. Membership is free and you can register by visiting: www.pcpld.org

Funding

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S Mitchell
Treasurer
August 2021

Palliative Care for People with Learning Disabilities (PCPLD Network)

Charity No: 1171355

Accounts for the 12 months ending 31st March 2022

Trustees

G Allen
C Gray
S Mitchell
Dr A Stewart
Prof I Tuffrey-Wijne
Dr S Yardley

Bank

Lloyds Bank - Andover Branch

Independent Financial Examiner

Mrs F Sykes
Retired Accountant

PCPLD Network
Charity No: 1171355

Balance Sheet to 31st March 2022

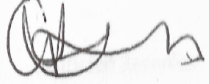
	Mar-22		Mar-21	
	£	£	£	£
Fixed Assets		0		0
Current Assets				
Lloyds Bank Debtors	1	£10,835.20 <u>1075.66</u>	£11,910.86	£13,451.46 <u>107.20</u>
Creditors		£0.00		£818.00
		<u>£11,910.86</u>		<u>£12,740.66</u>
Bailey Thomas Reserve Fund Free Reserves	2	0.00 5000.00 6910.86		3000.00 5000.00 4740.66
		<u>£11,910.86</u>		<u>£12,740.66</u>

1
2

Refund re National Awards - refunded to PCPLD Credit Card
Used to pay the costs of the website manager

Signed

PCPLD Trustee



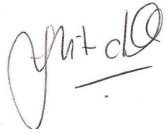
G Allen
Chair

Dated.

17/08/2022

PCPLD Trustee:

Signed:



S Mitchell
Treasurer

Dated:

11/08/2022

Signed

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 2022



Signed:

Mrs F Sykes - Retired Accountant

Dated:

13/09/2022

PCPLD Network
Charity No: 1171355

Sources & Application of Funds 2021/2022

	2021/22		2020/21	
	£		£	
Conference 21	5928.90	78%	0.00	
Donations - Others	1205.06	16%	145.30	
Donations - Webinars	337.83	4%	1165.53	
L McEnhil Awards	120.00	2%	0.00	
Amazon Smile	6.63	0%	0.00	
Lottery Community Fund			8832.00	
Bailey Thomas Trust			3000.00	
Training Delivered			250.00	
	<u>£7,598.42</u>	100%	<u>£13,392.83</u>	100%
Expenditure				
Website Manager	7170.00	85%	6510.00	
National Awards	606.34	7%	0.00	
Eventbright - Fees Conference	508.90	6%	0.00	
Webinar Ex's	428.45	5%	709.75	
Conference 21 Exp's	177.65	2%	0.00	
Zoom Sub 2021/22	143.88	2%	143.88	
Business email	105.66	1%	74.53	
Credit Card Fee	64.00	1%	32.00	
Double Click - Renew domain name	30.00	0%	0.00	
Misc	11.34	0%	0.00	
Lottery Community Fund -Accrual/Reverse	-818.00	-10%	818.00	
Website Admin	0.00	0%	960.00	
Photosymbol 10yr Licence	0.00	0%	900.00	
IT Equipment	0.00	0%	294.41	
Misc	0.00	0%	39.30	
	<u>£8,428.22</u>	100%	<u>£10,481.87</u>	
Excess Income over Expenditure	<u>-£829.80</u>		<u>£2,910.96</u>	
B/fwd	£12,740.66		£9,829.70	
C/fwd	<u>£11,910.86</u>		<u>£12,740.66</u>	
Restricted Reserves				
Bailey Thomas Trust	£0.00		£3,000.00	
Reserve Fund	£5,000.00		£5,000.00	
Unrestricted Reserves	£6,910.86		£4,740.66	
	<u>£11,910.86</u>		<u>£12,740.66</u>	

PALLIATIVE CARE FOR PEOPLE WITH LEARNING DISABILITIES NETWORK

England & Wales - Charity number 1171355

Accounts



PCPLD Network

Palliative Care for People with Learning Disabilities



ANNUAL REPORT 2020-2021

Palliative Care for People with Learning Disabilities Network

Email: info@pcpld.org

Twitter:

Registered Charity No: 1171355

Website: www.pcpld.org

@PCPLDnetwork

Introduction

This year has been marked by the uncertainties, challenges and the devastating impact of the COVID-19 pandemic. It has affected our PCPLD Network community, our colleagues working in health and social sectors, people who are most clinically vulnerable and those who have felt lonely and isolated.

Whilst it was a privilege to take over from interim Chair, Professor Irene Tuffrey-Wijne in September 2020, it hasn't been the easiest of years to lead a small charity. We have seen a significant change in the way that we source our income, after the cancellation of our 2020 Conference. However, PCPLD Network responded by successful collaborations with individuals and organisations, developing and leading the way in online educational webinars that were delivered to thousands of health and social care professionals and family carers.

We navigated change, explored different ways to generate income and adapted to new ways of working. We passionately and loudly campaigned for people with learning

disabilities, including the voices of people with lived experience and highlighted blanket DNACPR decisions and COVID-19 vaccines, hitting the BBC News headlines with our friends from the GRASSroots group.

This was only possible due to the determination, time, reassurance and courage of the Board of Trustees and Specialist Advisory Group. The PCPLD community is quite something and the support of our members this year has gone above and beyond. Together, we are ensuring that people with learning disabilities live well until they die, with equitable palliative and end of life care, including bereavement support.

There is much to celebrate and continue to build on in the coming year and I am delighted to share our Annual Report 2020-21 on behalf of the Board of Trustees.



Gemma Allen
Chair of PCPLD Network
August 2021

Trustees and Specialist Advisory Group

The Board of Trustees consist of six individuals, mainly from health and social care backgrounds. We have met this year on zoom and communicated regularly via email. Trustees make the overall decisions for PCPLD Network and are supported by the Specialist Advisory Group.

PCPLD Trustees:

- Gemma Allen (Chair)
- Dr Annie Stewart (Secretary)
- Steve Mitchell (Treasurer)
- Dr Sarah Yardley
- Professor Irene Tuffrey-Wijne
- Carol Gray

As required by PCPLD Network constitution, Gemma Allen and Steve Mitchell will retire from office and stand for re-election at the next AGM on 16th September 2021.

We are extremely fortunate to have sixteen individuals with a wealth of experience and knowledge about palliative care and/or learning disability on our Specialist Advisory Group. Since September 2020, the Specialist Advisory Group have met twice on zoom as a group, in addition to smaller meetings for work task groups.

Current Specialist Advisory Group:

- Pat Charlesworth (representing people with learning disabilities)
- Peter Allum (representing people with learning disabilities)
- James Benfield (representing people with learning disabilities)
- James Elmsworth (representing people with learning disabilities)
- Dr Jo Elverson (Consultant in Palliative Medicine, St Oswald's Hospice)
- Dr Valerie Potter (Consultant in Palliative Medicine, St Bartholomew's Hospital)
- Louise Jenkins (Strategic Lead Nurse, Hertfordshire Community Learning Disability Nursing Service)
- Louise Heatley (Retired support worker. Works in special educational needs)
- Kumar Cithambaram (Lecturer at School of Nursing and Midwifery, Queen's University)
- Sharon Prowse (Senor Manager, Freeway Bristol)
- Catherine Wood (Chief Executive Office. Representing family carers)
- Sian Mair Owen (Independent advisor in autism, learning disabilities and inclusion. Representing family carers)
- Jean Wilson (Representing family carers)

Webinars and conferences

In September 2020, we took the plunge of hosting online education events, moving our conference online with support from PCPLD Network Website Manager, Anastasiya Stravolemova, and the IT team at Kingston and St Georges University. This event attracted an audience of 1,700 people and was later viewed 1,800 times on YouTube. Feedback suggested the need for PCPLD Network to host regular webinars, so we formed a small working group to organise and deliver regular webinars. The team behind these events are Professor Irene Tuffrey-Wijne, Gemma Allen and Anastasiya Stravolemova, with additional support from Louise Jenkins and Sharon Prowse.

8 online education events have been delivered by PCPLD Network, with over 9,000 people attending!

PCPLD Network usual face-to-face conference is our only source of income and therefore the decision to alter the format of the 2020 conference was not taken lightly by the Board of Trustees. However, inspired by our previous events, we decided to run a full day online conference on 16th September 2021. We have planned a phenomenal programme with keynote speakers including

Professor Mark Taubert, Dr Katherine Mannix, Dr Jo Elverson and David Harling. A call for abstracts received an inspiring response of papers submitted that have allocated space within the agenda. It's not too late to book a place for our Annual Conference and you can do so [here](#).

Planning online events is time consuming and we could not do it without the dedication of the planning team and speakers. I would like to express my personal gratitude to everyone involved or who has participated this last year.

'The PCPLD Network are pioneers in raising the voices of people with a learning disability and educating those who are supporting them. I am learning so much from their inclusive webinars and passion for people with a learning disability to be recognised for the worth and value they hold. They confront the injustice and discrimination faced by people with a learning disability at the end of their lives (and during) with power and patience. An incredible example of how to campaign, share best practice and truly advocate for learning disabilities.'

Podcasts

Another new experience for PCPLD Network is podcasting! Whilst this remains in its early stages you can hear our current available podcasts by visiting PCPLD Network Soundcloud account. Again, thank you to everyone who contributed time and effort into these podcasts.

Membership

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Treasurer
August 2021

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(PCPLD Network)

Charity No: 1171355

Accounts for the 12 months ending 31st March 2021

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C Gray
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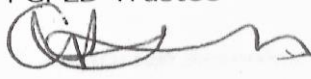

PCPLD Network
Charity No: 1171355

Balance Sheet to 31st March 2021

	Mar-21		Mar-20	
	£	£	£	£
Fixed Assets		0		0
Current Assets				
Lloyds Bank	£13,451.46		£10,229.70	
Debtors	1 <u>107.20</u>	£13,558.66	<u>320.00</u>	£10,549.70
Creditors		£818.00		£720.00
		<u>£12,740.66</u>		<u>£9,829.70</u>
Bailey Thomas		3000.00		
Reserve Fund		5000.00		5000.00
Free Reserves		<u>4740.66</u>		<u>4829.70</u>
		<u>£12,740.66</u>		<u>£9,829.70</u>

1 Donations made in 20/21 via Text donation and received in 21/22

2 Balance from the Lottery Grant to be refunded in 21/22

Signed		
PCPLD Trustee	G. Allen	Dated
		10/09/21
Signed		
PCPLD Trustee	S. Mitchell.	Dated
		8/1/21

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 2021.

Signed.



Dated

31/08/2021

Mrs F Sykes - Retired Accountant.

PCPLD Network
Charity No: 1171355

Sources & Application of Funds 2020/2021

	12 mths to March 2021		2019/20	
Income	£		£	
Lottery Community Fund	8832.00	66%		
Bailey Thomas Trust	3000.00	22%		
Donations - Webinar	1165.53			
Training Delivered	250.00	2%		
Donations - Others	145.30	1%	1.00	
	<u>£13,392.83</u>	100%	<u>£1.00</u>	100%
 Expenditure				
Website Manager	6510.00	62%		
Website Admin	960.00	9%		
Photosymbol 10yr Licence	900.00	9%		
Lottery Community Fund - Refund	818.00	8%		
Webinar - Exp's	709.75	7%		
IT Equipment	294.41	3%		
Zoom Subscription	143.88	1%		
Business email	74.53	1%		
Misc	39.30	0%		
Credit Card Fee	32.00	0%		
Away Day			347.70	34%
Website			673.85	66%
	<u>£10,481.87</u>	100%	<u>£1,021.55</u>	100%
 Excess Income over Expenditure	<u>£2,910.96</u>		<u>-£1,020.55</u>	
 B/fwd	£9,829.70		£10,850.25	
 C/fwd	<u>£12,740.66</u>		<u>£9,829.70</u>	
 Restricted Reserves				
Bailey Thomas Trust	£3,000.00			
Reserve Fund	£5,000.00		£5,000.00	
Unrestricted Reserves	£4,740.66		£4,829.70	
	<u>£12,740.66</u>		<u>£9,829.70</u>	