



# The PDA Society

Annual Report and Unaudited Financial Statements for the year ended  
31 March 2023

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## **The PDA Society**

### **Legal and administrative information for the year ended 31 March 2023**

#### **Trustees**

Sally Russell OBE	Chair	
Victoria Threlfall	Secretary, Vice-Chair, Comms Lead	Resigned February 2023
Paula Webb	Enquiry Line, Events and Safeguarding Lead	
Hilary Harvey	HR, Admin, Training and Forum Lead	
Jill Davis	Education Lead	
James Hulse	Fundraising Lead	
Sacha Wheatley	Inclusion Lead	Appointed 19 October 2022
Craig Mc Cormack	Treasurer	Appointed 19 October 2022

#### **Key management**

Helen Evans	Chief Executive	Resigned December 2022
Elizabeth Archer	Chief Executive	Appointed February 2023

#### **Principal Address**

PO Box 6080  
Sheffield  
S12 9EW

#### **Bankers**

HSBC  
5 Wimbledon Hill Road  
Wimbledon  
London  
Sw19 7NF

#### **Independent Examiner**

Susan Cochrane, FCA  
Seven Hills Accountants Limited  
57 Burton Street  
Sheffield  
S6 2HH

## The PDA Society

### Trustees' annual report

For the year ended 31 March 2023

#### Structure, governance and management

The Charity is a Charitable Incorporated Organisation, number 1165038 and is operated under the rules of its constitution, the documents of which are dated 5 January 2016. The charity previously operated as an unregistered group. The assets and liabilities of this organisation were transferred to the CIO on 1 April 2016.

Overall management of the charity is the responsibility of the trustees who are elected and co-opted under the terms of the constitution. Day to day project activity is managed and carried out by employees, trustees, self-employed contractors and volunteers.

#### Objectives and activities

To promote the relief of persons with Pathological Demand Avoidance (PDA) an Autistic Spectrum Disorder, and their families and carers, in particular, but not exclusively by:

- a.) Providing information, advice and support to those persons with PDA, their families and carers including those awaiting diagnosis, and
- b.) advancing the education of the general public, in particular those responsible for the care, treatment and diagnosis of PDA by raising awareness in all matters relating to PDA.

#### Overview & Activities During Financial Year

The PDA Society is the UK's only charity dedicated to supporting Autistic people with a Pathological Demand Avoidance (PDA) profile. Founded in 1997 by parents of PDA children and registered as a charity in 2016, we have 25 years' experience working with the PDA community to make positive change happen. We believe our biggest strength is being an organisation run by and for the PDA community. No-one understands the needs of our community better than us, or has the knowledge, skills or experience of PDA that we do, alongside the wider understanding of other activities and services currently available in the community.

PDA is an uncommon and complex presentation of autism, involving the avoidance of everyday demands and the use of social strategies as part of this avoidance. A PDA profile of autism is often missed, misdiagnosed and misunderstood, and conventional support approaches recommended for autism are typically ineffective and counter-productive.

As an organisation our overall aim is to facilitate improved quality of life outcomes for all PDA individuals and the people who support them by bringing the PDA community together to define and deliver the changes needed to improve the lives of PDA.

## Overview & Activities During Financial Year (continued)

We aim to achieve positive change within the community by giving PDA people and parents/carers a better understanding of PDA and the approaches that help, as well as confidence to self-advocate when engaging with professionals, a sense of belonging to a community that understands, and opportunities for meaningful paid work with the PDA Society. We also support this change by giving professionals (e.g. clinicians, teachers, social workers) more confidence and ability to identify PDA and apply PDA approaches, in turn giving PDA people improved access to a diagnosis and support that helps.

In response to this high level of unmet need, we support the PDA community through a range of different peer-led services, building strong relationships in and across the PDA community and helping people reach their potential by supporting them at the earliest possible stage. This year, we directly supported around 4,500 PDA people, parents/carers and professionals through our Enquiry Line, online forum, training, live Q&As and information resources.

## Enquiry Line and Peer Support

Between 1st April 2022 – 31st March 2023 our Enquiry Line provided 1,318 people with free practical and emotional support via Zoom, telephone or email delivered by peer supporters. We support on a range of issues including diagnosis, education and challenging behaviours, taking a person-centred, holistic approach.

Our enquiry line team members all have a direct connection to PDA and are specially trained to answer enquiries in a supportive, caring, and confidential manner. For enquiries about children, our team members who are parents to PDA children can help. For enquiries about adults, our team of PDA adults and parents of PDA adults can help.

The Enquiry Line enables people to feel more connected with the PDA community and less isolated, with improved mental and physical well-being. In our 2022 feedback survey, PDA adults gave our Enquiry Line service an average 7.3/10 for improved quality of life. We also received many positive comments, for example:

“Receiving support from the PDA Society parent line saved my relationship with my son and ultimately saved my life as I was suicidal from the lack of non-judgemental support.”

Our moderated Online Forum, with 5,900 registered users, is a safe virtual space for people to connect outside of social media. We also proactively promote and engage independent PDA Support Groups, offering opportunities for training and information resources as needed.



## Training and events

In the 22/23 year, 3,500 people attended our wide range of training courses and monthly live Q&As, providing specialist information about PDA and the approaches that help, delivered by trainers with lived experience. As a minimum, each course covers what PDA is, demands and their effects, how PDA can feel, helpful approaches (including collaborative problem solving) and signposting to resources & support.

A better understanding of PDA was scored an average 9/10 in our 2022 feedback survey, with attendees also benefitting from approaches that can help and more confidence to self-advocate when engaging with professionals (e.g. teachers, social workers, clinicians). It also helps the professionals who attend to better identify PDA and apply personalised approaches, giving improved access to diagnosis and helpful strategies.

This year we've also had an increasing number of requests from PDA people, parent carers and professionals for more in-depth topic-specific training. In response, we've undertaken work to develop new on-demand learning modules for PDA people and parents which we hope to launch in 2023.

## Information resources

Our information resources, including our website and social media platforms, provide the PDA community with the latest information about PDA, informed by lived experience and research, as well as signposting to in-person support groups, blogs from PDA adult advocates and more.

We know people can wait years for a neurodevelopmental assessment, typically 1 to 3 years for children being assessed by Child and Adolescent Mental Health Services (CAMHS), so it's particularly important people can freely access this information through our website or social media when they first suspect a PDA profile.

In 2022-23, over 750,000 people visited our website and we were followed by 84,756 people on social media. Our surveys showed that 87% of respondents reported benefits from accessing our information.

## Research

Understanding of PDA is in its early stages. Some clinics identify PDA as a profile of autism, whilst others don't recognise PDA because it's not listed in the diagnostic manuals. More research is needed before everyone can agree on what PDA is, what helps and its inclusion in the diagnostic manuals. Research needs to involve PDA individuals and the people who support them because PDA can't be properly understood without listening to the PDA community's lived experiences.

This year we have worked with the community to identify their PDA research priorities. We employed a one day a week research coordinator who is working establishing a PDA research network of like-minded professionals and is supporting the establishment of a PDA Centre of Expertise at an academic institution. As new research is undertaken, we will use this to inform our resources and training; and share it with policy makers to inform their decisions.

## The PDA Society

### Trustees' annual report

For the year ended 31 March 2023

## Partnerships

We've partnered with UK-wide and local organisations in the following areas:

**The PDA Community:** We partner with bloggers and authors from the PDA community, featuring them on our live Q&As, re-sharing their content on our social media platforms and in turn they promote us amongst their followers and readers. These partners include Sally Cat PDA, Riko's Blog, Julia Daunt, Kristy Forbes, PDA Dad, PDA Parenting, Positively PDA and Steph's Two Girls.

**Autism charities:** We collaborate with various organisations on our live Q&As, events and information resources. These have recently included Spectrum Gaming, (a charity dedicated to supporting Autistic young gamers), and A2ndVoice (a London based charity supporting the needs of Autistic people particularly from global majority and dual heritage communities). We have a good working relationship with the leading national autism charities.

**Health:** Partners include Help 4 Psychology, Psychiatry in London, Childrens Choice Therapy and Autism Associates.

**Education:** We recently signed a partnership agreement with Twinkl, one of the UK's leading publishers of educational materials for teachers. We have co-produce 5 educational resources for PDA learners and will develop a further 5 this year, building on our existing engagement with schools, with over 80 schools having received PDA Society training to date. Our events for the National Education Group and the National Education Union each reached hundreds of professionals.

**Social care:** We work with independent social workers, including award winning Vivacity Social Work, on projects of interest to the PDA community. Most recently this has included our Chair of Trustees being a cited author for the British Association of Social Workers' (BASW) new guidance for Fabricated and Induced Illness (FII), with false allegations being a common challenge for parents of PDA children, given poor awareness and understanding of PDA as a profile of autism.

## PDA Community Inclusion

Inclusion underpins our work – our first inclusion trustee was recruited in October 2023. One of our strategic objectives is to 'Be inclusive of all PDA individuals and the people who support them, working closely with the PDA community and other organisations to ensure PDA Society services are accessible and accountable.'

All services are delivered by the PDA community. Our Peer Supporters and Trainers are all either PDA adults or supporters of PDA people, as are the majority of our team. Our team survey showed 38% of staff, volunteers and trustees identifying as neurodivergent and 72% as carers. Of our core team of 5 employees, 4 are disabled. We empower the PDA community to feel valued as they are entrusted to deliver all our activities and take all our decisions. Beyond our team, we work closely with a panel of PDA adults.

## The PDA Society

### Trustees' annual report

For the year ended 31 March 2023

#### PDA Community Inclusion (continued)

Community fundraising events, with two successful fundraisers held in May 2022 with a 1.5 million steps campaign and Gaming Marathon delivered in partnership with Spectrum Gaming raising a combined total of over £10k

#### Staffing and structure.

In April 2022 we took on our first contracted team members, undertaking part time roles looking after our training, administration and communications functions. Trustees continue to lead areas of work around Communications, Training, Enquiry Line and research. We also recruited 2 new trustees via open recruitment Sacha Wheatley (Inclusion Lead) and Craig McCormack (Treasurer)

The number of active volunteers (excluding trustees) was 27 for this period.

The number of paid training facilitators (training facilitators are self-employed) was 25 at 31 March 2023. Please note that some of the paid training facilitators also carry out voluntary work with the PDA Society. The PDA Society now has 6 self-employed contactors for the enquiry line service.

#### Future Plans

The PDA Society is beginning year 2 of our Five-Year Strategy. This strategy has provided a road-map for the PDA Society's future plans. These include:

- Supporting 25% more people year-on-year through our Enquiry Line services
- Launching an Enquiry Line Plus service, offering enhanced support for people most in need
- Supporting between 5% to 10% more people year-on-year through our training services
- Launching on-demand learning, including modules for PDA adults and young people
- Seeking CPD accreditation for our training services and continue to invest in extended content
- Defining the top 10 unanswered PDA research questions with the PDA community
- Hosting an annual research conference, bringing researchers together with the PDA community
- Growing income so we have the funds needed to deliver our planned growth in services
- Investing in our systems, introducing a new CRM and HR database, to facilitate growth
- Updating our policies and procedures



## The PDA Society

### Trustees' annual report

For the year ended 31 March 2023

#### Future Plans (continued)

To deliver these planned activities (over next 4 years), the PDA Society will be aiming to grow its income in the coming years. Historically, the PDA Society has not pro-actively applied for grants from trusts and foundations. Going forward the PDA Society will be applying for a combination of large multi-year grants and small to medium sized grants. In addition, the PDA Society will be seeking to grow existing income from training, one-off giving and regular giving. We are relaunching our online shop in October 2023 and have our first corporate sponsor on board.

Our ability to deliver our Five-Year Strategy will be contingent on whether or not we can grow our income as planned. If we are unable to achieve this then it is our plan to sustain existing core services, until such time as we are able to secure sufficient income to grow our services.

#### Reserves Policy

The trustees aim to maintain free reserves in unrestricted funds at a level which equates to approximately six months of staffing and essential running costs. Currently this approximates to £111,227 based on budgeted expenditure for 2023/24. The trustees consider that this level will provide sufficient funds to deliver core services and ensure that office and governance costs are covered. The trustees consider that a level of six months is sufficient.

The balance held as unrestricted funds on 31 March 2023 was £135,007 (2022: £141,067). The balance held as designated funds on 31 March 2023 was £3,526 (2022: £39,115). These funds were designated to support the implementation of the strategic plan, published at the start of 2021/22. The Reserves Policy is reviewed annually by the Trustees.

#### Thank you to our supporters

The PDA Society is only able to make a difference because of the community that support us. The generosity of individuals, organisations and trusts donating their time, expertise and money to making life better for PDA people and people who love them. Thank you to everyone who has contributed this year.

The Trustees' declare that they have approved the above report on 7/12/2023 and are signed on their behalf by:



Name (printed) Craig McCormack

Position TRUSTEE / TREASURER

## **Independent Examiner's Report to the trustees of The PDA Society ("the Charity")**

I report to the trustees on my examination of the accounts of the Charity for the year ended 31 March 2023.

### **Responsibilities and basis of report**

As the charity trustees of the Trust 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 Trust'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 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: SCochrane

*Susan Cochrane FCA*  
Seven Hills Accountants Limited  
57 Burton Street  
Sheffield  
S6 2HH

Date: 18/12/2023

The PDA Society

Receipts & payments account

For the year ended 31 March 2023

	Notes	Unrestricted funds £	Restricted funds £	Total 2023 £	Unrestricted funds £	Restricted funds £	Total 2022 £
<b>Receipts</b>							
Charitable activities		98,363	-	98,363	82,678	-	82,678
Donations	2	60,831	-	60,831	54,172	-	54,172
Grants	3	6,250	9,659	15,909	24,160	-	24,160
Sale of merchandise		4,873	-	4,873	11,063	-	11,063
Book royalties		2,397	-	2,397	-	-	-
Other income		175	-	175	-	-	-
<b>Total receipts</b>		<b>172,889</b>	<b>9,659</b>	<b>182,548</b>	<b>172,073</b>	<b>-</b>	<b>172,073</b>
<b>Payments</b>							
General administrative expenses		3,091	385	3,476	3,649	-	3,649
Other professional expenses		844	2,030	2,874	67,590	-	67,590
Other expenses		6,214	-	6,214	782	-	782
Staff costs		115,804	-	115,804	-	-	-
Training facilitator		30,803	-	30,803	22,970	-	22,970
Enquiry line costs		11,593	-	11,593	9,230	-	9,230
Travel & accommodation		233	-	233	106	-	106
Postage, printing & stationery		1,484	-	1,484	2,106	-	2,106
Merchandise		1,587	-	1,587	4,195	-	4,195
Website		176	-	176	256	-	256
Insurance		1,062	-	1,062	608	-	608
Accountancy and business advice		825	-	825	-	-	-
Independent Examination fee		804	-	804	600	-	600
Paypal fees		133	-	133	191	-	191
Eventbrite fees- courses		4,296	-	4,296	2,787	-	2,787
<b>Total payments</b>		<b>178,949</b>	<b>2,415</b>	<b>181,364</b>	<b>115,070</b>	<b>-</b>	<b>115,070</b>
<b>Net receipts/(payments) for the year</b>		<b>(6,060)</b>	<b>7,244</b>	<b>1,184</b>	<b>57,003</b>	<b>-</b>	<b>57,003</b>
Total cash funds brought forward		141,067	-	141,067	84,064	-	84,064
<b>Total cash funds carried forward</b>		<b>135,007</b>	<b>7,244</b>	<b>142,251</b>	<b>141,067</b>	<b>-</b>	<b>141,067</b>

The PDA Society

Statement of assets and liabilities  
As at 31 March 2023

	2023 £	2022 £
<b>Cash assets</b>		
Bank balance	140,254	132,060
Paypal Balance	1,997	9,007
	<b>142,251</b>	<b>141,067</b>
<b>Fixed assets</b>		
Projectors	580	580
Other fixed assets	349	1,048
	<b>929</b>	<b>1,628</b>
<b>Other assets</b>		
Merchandise	2,036	2,493
Booklets	1,345	550
Charitable activities - income due	1,715	2,760
	<b>5,096</b>	<b>5,803</b>
<b>Liabilities</b>		
Accountancy & Independent examination fee	834	804
Other creditors	3,434	9,808
	<b>4,268</b>	<b>10,612</b>

Approved by the board of trustees on 7/12/2023 and signed on their behalf by;

Print name: Craig McCormack

Print name: JAMES HULSE

Position: TRUSTEE / TREASURER

Position: TRUSTEE



Notes to the accounts

For the year ended 31 March 2023

**1 Receipts & payments account**

Receipts and payments accounts are statements that summarise the movement of cash into and out of the organisation during the financial year. In this context "cash" includes cash equivalents, for example, bank accounts where cash can be readily withdrawn to pay for debts as they become due.

**Funds**

General funds are donations and other income received or generated for the objects of the organisation without further specified purpose and are available for general funds without restriction.

Restricted funds are either donations which the donor has specified are to be solely used for particular areas of the charity's work or grant income sought for specified activities.

**2 Donations**

	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total 2023 £</b>	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total 2022 £</b>
Donations	38,343	-	38,343	54,172	-	54,172
Community fundraising	22,488	-	22,488	-	-	-
	<b>60,831</b>	<b>-</b>	<b>60,831</b>	<b>54,172</b>	<b>-</b>	<b>54,172</b>

**3 Grants**

	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total 2023 £</b>	<b>Unrestricted funds £</b>	<b>Restricted funds £</b>	<b>Total 2022 £</b>
Ursula Ströher Stiftung	6,250	-	6,250	5,049	-	5,049
Aluminium Stockholders Association	-	-	-	19,111	-	19,111
Jonathan de Pass	-	9,659	9,659	-	-	-
	<b>6,250</b>	<b>9,659</b>	<b>15,909</b>	<b>24,160</b>	<b>-</b>	<b>24,160</b>

#### 4 Trustees remuneration, benefits and expenses

No trustee received the following expenses during the financial year (2022: Two trustees), not including those payments listed under the related party transactions.

	<b>Total 2023</b>	<b>Total 2022</b>
	<b>£</b>	<b>£</b>
Travel and Accommodation	-	109
	<u>-</u>	<u>109</u>

The following trustees were paid during the financial year for services provided to the organisation as follows:

Name	Services Provided	<b>Total 2023</b>	<b>Total 2022</b>
		<b>£</b>	<b>£</b>
Jilly Davies	Workshop Facilitation	2,250	1,550
		<u>2,250</u>	<u>1,550</u>

Trustees donated £120 (2022: £4,120) before gift aid without conditions.

The son of S Russell, a trustee, was paid £415 to provide training services to the charity.

No other payments other than those shown in this note were paid to trustees.

#### 5 Designated funds

	<b>Balance at 01-Apr-22</b>	<b>Income</b>	<b>Expenditure</b>	<b>Transfers</b>	<b>Balance at 31-Mar-23</b>
Strategic growth fund	39,115	-	(35,589)	-	3,526
	<u>39,115</u>	<u>-</u>	<u>(35,589)</u>	<u>-</u>	<u>3,526</u>

During the year funds were designated for strategic planning and organisational growth (principally CEO consultancy costs

*Prior year*

	<b>Balance at 01-Apr-21</b>	<b>Income</b>	<b>Expenditure</b>	<b>Transfers</b>	<b>Balance at 31-Mar-22</b>
Strategic growth fund	-	-	(30,531)	69,646	39,115
	<u>-</u>	<u>-</u>	<u>(30,531)</u>	<u>69,646</u>	<u>39,115</u>

## 6 Restricted funds

	Balance at 01-Apr-22	Income	Expenditure	Transfers	Balance at 31-Mar-23
PDA Research fund	-	9,659	(2,415)	-	7,244
	<u>-</u>	<u>9,659</u>	<u>(2,415)</u>	<u>-</u>	<u>7,244</u>

### PDA Research fund

Funding to contribute towards the five year research goal to "Promote high quality multi-disciplinary research to extend understanding of PDA and the approaches needed, informing policy and practice, with improved outcomes for PDA