



Year ending 5 April 2022

PANS PANDAS UK



Annual Report 2021/22

Introduction

As Chair of PANS PANDAS UK, I am pleased to present the Annual Report for 2021-22.

The aim of this report is to explain, in plain English, what the Charity has achieved, and how our income has been used to further our aims.

There was a great deal of change in the reporting year 2021-22. I started as Chair in February 2022, succeeding Georgia Tuckey the co-founder and inaugural Chair of the Charity.

Georgia brought her own style of no-nonsense leadership to the charity ensuring that the focus was solely on the families affected by the conditions. Georgia's vision and commitment to the families saw her proposing to add advocacy to the charitable objectives and this was done in 2020. A fierce advocate for the affected families, Georgia was widely respected and loved by the community and we wish her well in her future endeavours and thank her for setting the foundation stone of the charity.

Another important change was the appointment of a CEO to support the Board of Trustees in drafting a new strategy and to manage the daily operations of the Charity.

I am delighted to bring you this report outlining our achievements over the last year and also with a taster of what is to come in the year ahead.

I thank the Trustees and all the volunteers for their invaluable contribution to the Charity. We could not achieve a fraction of the important work we do without their dedication. I also want to acknowledge every single person who has undertaken a fund-raising challenge, or set up a fundraiser, donated or shared a post on social media. All awareness raised or income received is because of the efforts of our supporters and we are so very grateful to them.

This report is laid out in the following manner:

[Section 1:](#) What are PANS and PANDAS, and what is PANS PANDAS UK

[Section 2:](#) This Annual Report - General

[Section 3:](#) Meeting Our Legal Requirements

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Section 1: What are PANS and PANDAS, and what is PANS PANDAS UK?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Auto-immune, Neuropsychiatric Disorders Associated with Streptococcal Infections) are a set of immune-mediated conditions causing a variety of neuro-psychiatric conditions such as OCD, tics and eating disorders in addition to other equally distressing symptoms. These are cruel and complex conditions which require a multi-disciplinary team of medical professionals as well as understanding and support from schools and in some cases social care to ensure the very best support is offered to affected families.

PANS PANDAS UK operates nationally and established as an organisation in 2017, first creating a network of doctors called the PANS Physicians Network with a view to improving understanding and awareness amongst medical professionals. The charity then set up the Facebook support group and started to provide resources on their website and social media channels in order to support families living with the conditions. Charity status was achieved on 22 May 2018. More recently the Charity is providing training for educational professionals so that they may better support affected pupils in the classroom, and where they may be too ill to attend school to offer alternative resources.

Please visit our website for more information:

www.panspandasuk.org

Section 2: This Annual Report - General

This Annual Report for the financial year 2021-22 explains our aims and how we have gone about achieving them.

It has been prepared in accordance with the applicable legal requirements.

It gives a balanced view of the charity's structure, aims, objectives, activities and performance. Importantly, it describes our primary sources of funding, and describes how the money was spent.

It highlights the main activities we have undertaken.

Section 3: Meeting Our Legal Requirements

SORP (FRS 102) is the Charity Commission's Statement of Recommended Practice - Accounting and Reporting by Charities. We have therefore prepared this report, and our accounts, in accordance with that guidance, as we were founded after 1 January 2016.

Because our income lies between £25,000 and £250,000, we have prepared our accounts on a "Receipts and Payments" basis. This means that our accounts contain a statement summarising all money received and paid out in the financial year, and a statement of our assets and liabilities at the end of the year. Our accounts have been subject to independent examination.

The detailed legal requirements for this report are set out in The Charities (Accounts and Reports) Regulations 2008 which provide a legal underpinning for many of the recommendations made in the applicable Charities SORP.

The headings used in our report follow this guidance, as follows:

- Reference and administrative details;
- Structure, governance and management;
- Objectives and activities;
- Achievements and performance;
- A financial review;
- Funds held as custodian trustee on behalf of others;
- Public benefit statement.

Section 4: Reference and Administrative Details

4.1 The Charity's Name

The Charity's name is PANS PANDAS UK.

4.2 The Charity's Registration Number

The Charity's number is 1178484..

4.3 The Address of the Principle Office

The Charity does not operate from premises, but by a network of people operating from their own homes. The Charity's formal legal contact is through the Secretary and Chair Elect, Mrs Vicky Burford, Lowfield, Long Itchington Road, Offchurch, Leamington Spa, CV33 9AY.

The Charity's Registered Office is as follows:
Greville House, 10 Jury Street, Warwick CV34 4EW

4.4 Names of Charity's Trustees

- **Chair:** Mrs Georgia Marie Tuckey (Resigned February 2022)
- **Chair:** Mrs Vicky Burford (Appointed February 2022)
- **Treasurer:** Mr Philip Edwin Hall
- **Trustee:** Zoe Van Den Bosch
- **Trustee:** Cindy Hvid (Resigned February 2022)
- **Trustee:** Sarah Hughes (Appointed April 2022)
- **Trustee:** Diane Palmer (Appointed April 2022)

No other people served as a charity trustee or custodian trustee in the last financial year.

Section 5: Structure, Governance and Management

5.1 Particulars of the Governing Document

The Charity has a formal Constitution, which was approved by the Charity Commission on 22 May 2018. The Charity is run by the Trustees, as a management committee. The Trustees may be appointed at any time by the management committee.

The Charity operates by means of committee meetings, held on a video-conference basis, or physically meeting if necessary. The minutes of the meeting are formally recorded by the Secretary/Chair.

Section 6: Objectives and Activities

6.1 The Purposes of the Charity

The purposes of the charity are to carry out its charitable objectives which are outlined below:

"To advance the education of the general public in all areas relating to the medical conditions PANS (Paediatric Acute-Onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections)."

"The provision of one-to-one support, education, practical advice and advocacy to the sufferers (and families) of the medical conditions PANS and PANDAS."

6.2 The Main Activities Undertaken

Over the last year, we have:

- held our Annual General Meeting (AGM);
- appointed a Chief Executive Officer (CEO);
- held a strategy- building away day;
- undertaken a Governance audit;
- continued to grow the PANS Physician's Network UK;
- raised over £89,000 in fundraising activities;
- held further All-Party Parliamentary Group (APPG) meetings;
- delivered CPD Accredited Training for educators;
- funded research projects;
- created a "PANS Guide for Parents" book;
- attended the James Lind Alliance Priority Setting Workshop into childhood neurological research;
- met NHS England to further health development;
- appointed a Charity Ambassador;
- continued developing our media presence;
- announced Greater Birmingham Chamber of Commerce as our nominated charity;
- attended the Birmingham Chamber Annual Awards Ceremony;
- appointed interns
- appointed a Patient Information Executive;
- implemented a regular newsletter programme.

6.2.1 Annual General Meeting (AGM)

The AGM was held in July 2021 via Zoom due to the Coronavirus Pandemic.

The Trustees of the Charity were joined by 47 Individuals from the community.

Diane Palmer, Associate Director of Nursing for Norfolk and Suffolk Foundation Trust was the guest speaker and was very well received. Following the 'business' part of the meeting, service-user feedback was encouraged, and a number of useful suggestions were made, the principal one of which about the need for a CEO.

6.2.2 Appointment of a Chief Executive Officer

Following recommendations by our service-users, and an assessment of our current working capacity and resources, the trustees agreed that it was the right time to advertise for a CEO.

Following a rigorous recruitment campaign, using the services of an independent charity consultant, Dan McLean was successfully appointed in January 2022 as the charity's very first member of staff.

6.2.3 Strategy Building Away-Day

Following the appointment of the CEO, it was decided that this was a good opportunity to gather the trustees and the executive team together to identify where we are as a charity, and how we could improve on what we are offering to our community. A two-day workshop was held, with an external moderator, near Birmingham.

The workshop proved extremely valuable and a new draft strategy was developed. The draft strategy will be shared with a variety of service-users and stakeholders before being formally announced to the community at the AGM in July.

6.2.4 Governance Audit

Following the strategy away-day with the leadership team, one of the key areas discussed was that of Governance. As a result, we engaged a volunteer with extensive governance experience to undertake a Governance audit of the charity. Her report demonstrated that we were fulfilling all our legal obligations and that whilst there is always room for improvement, for a charity of our size we are doing very well indeed. Improvements are being continuously made and we will continue to review our governance procedures regularly to ensure that we offer best practice.

6.2.5 Continued to grow the PANS Physician's Network

Having become used to meeting virtually since the first Coronavirus lockdown, we have continued to meet via Microsoft Teams even after social restrictions were eased in order to remain as accessible as possible to the wider medical community. We have seen a larger number of medical professionals attending these meetings as there is no requirement for travel. The meetings still take place quarterly and are open to all medical professionals with an interest in the conditions.

6.2.6 Raised over £89,000 in Fundraising Activities

The Charity has been extremely fortunate to receive a large number of generous donations and has been the recipient of many fundraising activities during 2021/2022.

Following the success of their first-ever charity-led fundraising campaign in 2020, The Big Give's Christmas Challenge, the Charity undertook this same fundraiser in 2021 and raised a total of just over £11,800, further supplemented by nearly £700 of Gift Aid donations.

The vast majority of our fund-raising income was accounted for by individuals' contributions (over £15,600) and by community fundraising activities (over £61,000).

Notable community fundraisers during this financial year include:

- Neil Gilson's Swansea to Ilfracombe Channel Swim and Raffles raising over £15,000
- Matt Blyth's 3 Peaks in 24 hrs and Dunwich Dynamo 140-mile cycle challenge raising nearly £14,000
- Eva Knowles' Sponsored Swim raised over £1,000
- Olivia Preston's 30 cold showers raised £2,422.85
- Konner Vanderpal's 24-hour gaming stream raised £213.75
- Leah Midgley's Leeds half marathon raised £634.41
- Holly Wheeler's Skydive raised £8,512.33
- Cameron Sharp's Chase the Sun raised £1,309.63
- Simon Taylor and Team 'TayLewUbb's' 3 Peaks raised £1,936.54
- Dawn Scott and Louise McQuarrie's Leicester half marathon raised £1,029.91
- Kelly Lee's Twilight Runway Challenge raised £466.36
- Birmingham Chamber Awards Ceremony raised over £10,000

6.2.7 All Party Parliamentary Group (APPG)

Further meetings of the APPG for PANS and PANDAS took place via Microsoft Teams during 2021 and 2022. These meetings were attended by a good number of MPs, Peers of all parties, parent representatives and health care professionals in order to continue the APPG process. From April 2022, APPG speakers are required to attend Parliament in person.

6.2.8 CPD Accredited Training for Educators

5 CPD Accredited training events were rolled out to approximately 200 individuals during this financial year. 3 events were held with Norfolk County Council and those in attendance included educational psychologists, specialist support team, medical needs team including the Designated Clinical Officers and the inclusion team.

One training session was delivered to an individual school with attendees including teachers, leadership team and SENCO's (Special Educational Needs Co-ordinators) and one further training session was delivered in collaboration with Neurodivergent Education Support and Training (NEST) who deliver training to a variety of educational providers.

Development on training for social workers and health visitors was also started during this financial year

6.2.9 Funded Research Projects

In 2021-22, PPUK donated £2,000 to a small UK led research project with Oxford University looking at L-form organisms.

A further £4,799 was part funding towards a European grant application entitled 'Designing a cost-effective diagnostic route for PANS patients' with Catalyze.

We look forward to announcing more details of the outcomes of these research projects in due course[

6.2.10 Book

Work continued on the 'Guide to PANS and PANDAS' book which aims to cover all areas of PANS and PANDAS and is aimed primarily at families living with the conditions. It includes illustrated real-life stories from individuals who have experienced PANS or PANDAS.

6.2.11 James Lind Alliance Priority Settings Workshop

The Chair of the Charity attended the James Lind Alliance Priority Settings Workshop into childhood neurological conditions along with the parent of a child with PANS to represent the PANS community in identifying the top priorities for childhood neurological research.

This workshop, led by the James Lind Alliance aimed to identify the top ten priorities for research in childhood neurological conditions. We are grateful that research into PANS and PANDAS was well supported.

The results will be published in September 2022

6.2.12 Met representatives from NHS England and NHS Improvement

The charity held an inaugural meeting with representatives from NHS England in order to discuss the need for NICE (National Institute for Health and Care Excellence) guidelines. This has led to the following action points:

- PANS PANDAS UK to continue to work with different professional bodies to highlight challenges for Children and young people and their families
- PANS PANDAS UK to host roundtable in September and invite range of stakeholders including professional bodies (Terms of Reference and objectives to be agreed in advance)
- NHS England to approach Royal College of Paediatrics and Child Health to discuss current challenges, need for clinical consensus and input/leadership from Royal College of Paediatrics and Child Health in supporting clinical consensus
- NHS England to bring agenda item to [VB1] [VB2] the Mental Health Action Group on challenges/need for clinical consensus from professional organisations
- PANS PANDAS UK to highlight research gaps/priorities to NHS England including those agreed by James Lind Alliance
- NHS England to highlight research gaps/priorities to National Institute for Health Research

6.2.13 Appointed a Charity Ambassador

We are delighted to announce that UK actor Jo Joyner has agreed to be our first Charity Ambassador and we are so grateful for the increased awareness this will bring. There are many plans in the pipeline and these will be announced in due course.

6.2.14 Continuing Media Presence

We increased our social media awareness through the mechanism of parents from the support group tweeting various celebrities, scientists, medical professionals and MP's.

Some notable pieces of media coverage include a Channel 5 news item featuring stories from two families. Well-being expert Liz Earle interviewed Nutritionist Stella Chadwick in her blog which was very well received indeed. Work was underway on a double page spread in the next Liz Earle Magazine, due to be released in May 2022 to highlight the plight of families affected by PANS and PANDAS.

6.2.15 Birmingham Chamber of Commerce, nominated Charity

The President of the Greater Birmingham Chamber of Commerce has chosen PANS PANDAS UK as her nominated charity for the two years of her appointment from March 2022 to March 2024. In the short time since we were nominated in March 2022, we have attended the Annual Award Ceremony and received over £10,000 in fundraising from this one event and have been introduced to a number of influential and supportive people.

We look forward to building a very fruitful relationship.

6.2.16 Interns

We have built relationships with the University of Birmingham Business Centre and have been fortunate to receive applications from a number of students looking for internships. Interviews have taken place and interns will be starting their placements during the summer of 2022.

6.2.17 Appointed a Patient Information Executive

We have appointed a volunteer to focus solely on developing and improving our patient information. This includes our website content, resources, media and training information.

6.2.18 Implemented a Regular Newsletter

Following feedback from our community, we started sending out our newsletter on a more regular basis. Rather than annually, or bi-annually as in previous years, in 2021 we started sending out the newsletter every 4-6 weeks to a growing mailing list of 1158 which has enabled us to keep our community up-to-date with progress within the charity.

Feedback has been positive.

6.3 Statement of Compliance

The Trustees believe they have complied with the duty in Section 4 of the 2006 Act in having due regard to guidance on public benefit published by the Charity Commission.

Section 7: Achievements and Performance

We report on our performance and achievements on several measures.

7.1 Our Main Mission

Our main mission is to ensure that PANS and PANDAS are recognised and understood in every GP Surgery, every school and every hospital. This is a long-term goal and will take some time to accomplish. Whilst we have not achieved this mission at this early stage, we are making good headway towards raising awareness in all of these areas as we described in Section 6.

7.2 "Members"

Currently PANS PANDAS UK does not have a formal membership structure for the charity; we count the members of the facebook support group as our membership.

Currently, there are 4,745 members of the PANS PANDAS UK Support Group which is an increase of 1,124 since 5th April 2021.

7.3 Service User Feedback

The following quotes are representative of the feedback the charity has received. Some of these individuals have received direct support from the charity and others are members of the online support group.

"It doesn't feel as lonely and hopeless with you all on board and fighting for our children! Without PANS PANDAS UK charity we would just be unheard."

"Thank you, thank you for all of your hard work. We all know how tirelessly you are all working to get us all help and recognition. Thank you."

"Thank you all for doing this and your ongoing support! Our children are our world and we appreciate everything you do!"

"Thank you for fighting our corner and not giving up!"

Section 8: Financial Review

8.1 The Reporting Period for this Report

The Charity's financial performance reported below is for the period from 6 April 2021 to 5 April 2022.

8.2 Our Accounts and Bankers

The Charity operates using only one bank account, as follows:

Santander Business Account

Sort Code: 09 01 29

Account Number: 23328323.

8.3 Financial Results: Receipts and Payments, and Assets and Liabilities

For 2021-22, we prepared our accounts on a "Receipts and Payments" basis, which means that we recorded cash flows in and out during the accounting period. The slight disadvantage in this approach is that some known future income, and some known expenditure, are not recorded. The magnitude of these known sums is minor in respect of the total turnover, and the financial position of the Charity.

Looking ahead to the financial year 2022-23, we intend to use HMRI-approved accountancy software known as "Xero" to replace the spreadsheet method. The principles of accountancy remain the same, but there will be different income and expenditure headings. The software also presents the opportunity to better account for known future income and expenditure. In order to ensure continuity and consistency between the spreadsheet method and the Xero method, the accounts for the reporting year were actually developed using both methods in parallel. There was an exact match, so we are confident moving forward with the Xero approach. The Independent Examiners were presented with both sets of results.

We have more rigorously segregated our accounts into restricted and unrestricted funds.

Restricted funds currently fall into only one category which we describe as 'research', but which in fact encompasses funds intended by donors to be used to advance medical and scientific knowledge and understanding of the causes, treatment and management of PANS and PANDAS.

The Assets and Liabilities Statement makes an assessment of these sums, in order to present the current status in respect of assets or liabilities.

The sheet overleaf (Form CC16a) presents the financial performance using the Charity Commission's reporting Form CC16a. This form records:

- Section A: The Receipts and Payments during the financial year;
- Section B: The Assets and Liabilities of the Charity at the year end.

The assets of the Charity are the funds in our Santander Account, as that is the only account we hold. The Independent Examiner agreed that a separate Assets and Liabilities Statement was not needed, as the Charity's cash position represented its assets.

We have no fixed or material assets of any significance; we only hold trivial items such as stocks of stationery etc.

We have no property assets.

The assets and liabilities have been independently scrutinised, and the Independent Examiner has prepared a statement of conformity.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name
PANS / PANDAS UK

No (if any)
1178484

CC16a

Receipts and payments accounts

For the period
from

Period start date
06/04/2021

To

Period end date
05/04/2022

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					
Fund raising	77,563	12,777	-	90,340	50,489
Exhibitors / Awareness	140	-	-	140	238
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	77,703	12,777	-	90,480	50,727
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	77,703	12,777	-	90,480	50,727
A3 Payments					
Fund raising	4,582	-	-	4,582	16,959
Project costs	20,655	6,799	-	27,454	-
Exhibitor / Awareness	5,277	-	-	5,277	1,563
Staff costs	18,164	-	-	18,164	-
Administration	3,502	-	-	3,502	-
Professional fees	4,141	-	-	4,141	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	56,321	6,799	-	63,120	18,522
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	56,321	6,799	-	63,120	18,522
Net of receipts/(payments)	21,382	5,978	-	27,360	32,205
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	30,296	24,323	-	54,619	22,415
Cash funds this year end	51,678	30,301	-	81,979	54,620

Independent examiner's report to the trustees of PANS PANDAS UK

I report on my examination of the accounts of the charity ("the Trust") for the year ended 5th April 2022

Responsibilities of Trustees and Examiner

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 which gives me cause to believe that in, any material respect:

- The accounting records were not kept in accordance with section 130 of the Charities Act; or
- The accounts did not accord with the accounting records; or
- The accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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.



Steven Mugglestone BA (Hons) FCA
Michael Harwood & Co
Chartered Accountants
Greville House
10 Jury Street
Warwick
CV34 4EW

19 July 2022

8.4 Policies on Reserves

We seek to hold a minimum bank balance equating to 6 months' turnover. This provides a more than sufficient buffer to allow us to meet our obligations, to undertake our activities, and to pay our suppliers promptly. We will review this reserves policy in the light of more operational experience.

8.5 Funds in Deficit

We do not have any funds in deficit. Our only funds are, as has been described, held in the Santander account. This is in healthy surplus.

Section 9: Funds Held as Custodian Trustee on Behalf of Others

PANS PANDAS UK does not hold any assets in respect of other charities..

Section 10: Public Benefit Statement

We believe we have complied with the duty to have due regard to the guidance on public benefit published by the commission in exercising their powers or duties.

Section 11: Plans for Future Periods

Although only larger charities subject to statutory audit are required to provide details of plans for future periods, we nevertheless provide headlines for activity in the financial year 2022/23:

- Continue with APPG and follow up recommendations from MPs;
- Fund more research in relation to PANS and PANDAS in the UK;
- Develop and implement a comprehensive fundraising plan for Charity stability;
- Implement the use of a Customer Relationship Management Package in order to be in effective contact with people and maintain legal data records;
- Republish the website for people affected by PANS & PANDAS
- Update the patient information resources available to our community;
- Build an excellent and growing resource library for patients and families;
- Deliver training events to regional SEN (Special Educational Needs) professionals;

- Continue to disseminate condition information and awareness to schools;
- Build condition data/evidence through a national patient survey;
- Engage with Royal Colleges and NHS England, Scotland, Northern Ireland and Wales;
- Work on developing stronger relations with our European Counterparts;
- Develop the Board of Trustees, staff and volunteer skills;
- Create part time posts for 3 roles – information, schools, contacts

11.1 All Party Parliamentary Group (APPG)

Following a number of virtual meetings with the APPG[DM1] [VB2] , recommendations are outlined below:

- Request that MPs engage in conversation with Secretary of State for Health and Social Care.
- Pair specific asks with parliamentary action with the goal of NHS approval of treatment process in accordance to UK guidelines.
- MPs to request meeting with Dept Health and Social Care
- Charity to organise meetings with NHS England, NHS Scotland, NHS Wales, NHS Health and Social Care Northern Ireland and Health Education England.

A number of these recommendations are underway.

11.2 Fund more research in relation to PANS and PANDAS in the UK

With £30,301 reserved for UK-led research the charity will invite applications for funding.

11.3 Implement a comprehensive Fundraising Plan

The charity will write and implement a comprehensive fundraising plan during 2022-23 in order to ensure that we remain a sustainable organisation moving forward. This will include community fundraising events, wider events put on by the charity and applications for grants.

11.4 Implement the use of a Customer Relationship Management Package (CRM)

PPUK intends to install a new CRM package in order to streamline recording of fundraising, and more effective management of stakeholders going forward.

11.5 Republish the Website

A substantial review of the website will take place during 2022-23 in order to make the website more user friendly and accessible. The language will become friendlier and clearer and in line with PIF (Patient Information Forum) recommendations.

11.6 Update the Patient Information Resources available to our Community

A review of the patient information resources will also take place during 2022-23 to ensure that our existing resources are clearly written, accessible and still fit for purpose.

11.7 Build an excellent and growing resource library for patients and families

We plan to employ a member of staff in 2022-23 to focus on patient information and to build an excellent resource library for patients of all ages and their families.

11.8 Deliver training events to regional SEN (Special Educational Needs) professionals

We plan to employ a part time education professional to focus on delivering CPD accredited training events to regional SEN professionals, DCO's and schools throughout the UK.

11.9 Continue to disseminate condition information and awareness to schools

We will continue to ensure that condition information and awareness resources are shared with schools around the country throughout 2022-23.

11.10 Build condition data/evidence through a national survey

Working with the BPNA (British Paediatric Neurological Association), we plan to undertake a national survey to develop a better understanding of the incidence of PANS and PANDAS in the UK and gain a clearer insight into the impacts of these conditions on patients and families.

11.11 Engage with the Royal Colleges and NHS England, Northern Ireland, Wales and Scotland

Working with the BPNA (British Paediatric Neurological Association), we propose to continue building relationships with the Royal Colleges and NHS England, Wales, Northern Ireland and Scotland to develop a realistic and achievable clinical pathway for effective treatment. We seek to understand the impacts of the BPNA Consensus Statement and build new consensus for the PANS Physician's guidance.

11.12 Developing stronger relationships with our European Counterparts

We plan to work closely with EXPAND (an organisation representing PANS patient organisations from all over Europe) to develop stronger relationships with their Scientific and Medical Advisory Board and other European organisations representing the PANS community.

11.13 Develop the Board of Trustees, staff and volunteer skills

The Board of Trustees currently enjoys a wide range of skills, but a skills audit will be carried out on an annual basis and training will be offered to those already on the board in order to improve their skills. PPUK is also committed to offering training to the Staff and Volunteers in order to encourage life-long learning, and personal and professional development.

Section 12: Signed Statement

I, Vicky Burford, hereby sign this Annual Report as a true record of the activities of the Charity for the year from 6th April 2021 to 5th April 2022.

Signed:

A handwritten signature in black ink, appearing to read 'Vicky Burford', written over a faint horizontal line.

Name:

Vicky Burford

Position:

Chair of Trustees, PANS PANDAS UK

Date:

18th July 2022

Having been duly authorised to do so by the Trustees of the Charity.

**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 5 APRIL 2022
FOR
PANS / PANDAS UK**

Michael Harwood & Co
Chartered Accountants
Greville House
10 Jury Street
Warwick
Warwickshire
CV34 4EW

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for the Year Ended 5 April 2022**

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PANS / PANDAS UK

REPORT OF THE TRUSTEES for the Year Ended 5 April 2022

The trustees present their report with the financial statements of the charity for the year ended 5 April 2022. The trustees have adopted the provisions of Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019).

OBJECTIVES AND ACTIVITIES

Objectives and aims

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Auto-immune, Neuropsychiatric Disorders Associated with Streptococcal Infections) are a set of immune mediated conditions causing a variety of neuro-psychiatric conditions such as OCD, tics and eating disorders in addition to other equally distressing symptoms. These are cruel and complex conditions which require a multi-disciplinary team of medical professionals as well as understanding and support from schools and in some cases, social care to ensure the very best support is offered to affected families.

PANS PANDAS UK (PPUK - called "we" or "us") is a UK-wide Charity which was established as an organisation in 2017, first creating a network of doctors called the PANS Physicians Network with a view to improving understanding and awareness amongst medical professionals. The charity then set up the Facebook support group and started to provide resources on their website and social media channels in order to support families living with the conditions. Charity status was achieved on 22 May 2018. More recently the Charity is providing training for educational professionals so that they may better support affected pupils in the classroom, and where they may be too ill to attend school to offer alternative resources.

Please visit our website for more information:

www.panspandasuk.org

FINANCIAL REVIEW

Going concern

Although the Covid restrictions were still in force for much of the financial year 2021-22, our fund-raising events seem not to have remotely suffered, and they contributed £61K towards our total income of £90K; this total was a 76% increase on 2020-21. This is a very healthy position. The expenditure increase was £18k on staff and an additional £20k on other charity activity in terms of the increases on 2020/21. The surplus on the year was £25K, which, added to the assets carried over in April 2021, provided us with a healthy balance of £80K at the end of the financial year.

Looking forward to 2022-23, the CEO will be in post for a full year, with a consequential increase in costs, albeit offset by lower outgoings on professional fees. His appointment also increases the opportunities to grow our fund-raising income. We forecast a planned deficit in 2022-23. We forecast that our assets by the end of 2022-23 will be very comparable to the current level.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

The charity is controlled by its governing document, a deed of trust and constitutes an incorporated charity.

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1178484

Principal address

Lowfields
Long Itchington Road
Offchurch
Leamington Spa
CV33 9AY

Trustees

Mrs G Tuckey (resigned 10.2.22)
Mrs V Burford
Mr P Hall
Ms C Hvid (resigned 10.2.22)
Ms Z Van Den Bosch
Ms S Hughes (appointed 27.4.22)
Ms D Palmer (appointed 26.4.22)

PANS / PANDAS UK

**REPORT OF THE TRUSTEES
for the Year Ended 5 April 2022**

REFERENCE AND ADMINISTRATIVE DETAILS

Independent Examiner

Michael Harwood & Co
Chartered Accountants
Greville House
10 Jury Street
Warwick
Warwickshire
CV34 4EW

Approved by order of the board of trustees on 2 July 2022 and signed on its behalf by:

Mrs V Burford - Trustee

**INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF
PANS / PANDAS UK**

Independent examiner's report to the trustees of PANS / PANDAS UK

I report to the charity trustees on my examination of the accounts of PANS / PANDAS UK (the Trust) for the year ended 5 April 2022.

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 Act and in carrying out my examination I have followed all 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 the Trust as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a true and fair view which is not a matter considered as part of an independent examination.

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.

Steven Mugglestone
BA (Hons) FCA
Michael Harwood & Co
Chartered Accountants
Greville House
10 Jury Street
Warwick
Warwickshire
CV34 4EW

2 July 2022

PANS / PANDAS UK

**STATEMENT OF FINANCIAL ACTIVITIES
for the Year Ended 5 April 2022**

	Notes	Unrestricted fund £	Restricted fund £	5.4.22 Total funds £	5.4.21 Total funds £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		77,703	12,777	90,480	50,726
 EXPENDITURE ON					
Charitable activities		56,321	6,799	63,120	18,522
 NET INCOME		21,382	5,978	27,360	32,204
 RECONCILIATION OF FUNDS					
Total funds brought forward		30,296	24,323	54,619	22,415
 TOTAL FUNDS CARRIED FORWARD		51,678	30,301	81,979	54,619

The notes form part of these financial statements

PANS / PANDAS UK

BALANCE SHEET
5 April 2022

	Notes	Unrestricted fund £	Restricted fund £	5.4.22 Total funds £	5.4.21 Total funds £
CURRENT ASSETS					
Debtors	4	1,860	-	1,860	-
Cash at bank		49,818	30,301	80,119	54,619
		51,678	30,301	81,979	54,619
NET CURRENT ASSETS		51,678	30,301	81,979	54,619
TOTAL ASSETS LESS CURRENT LIABILITIES		51,678	30,301	81,979	54,619
NET ASSETS		51,678	30,301	81,979	54,619
FUNDS	5				
Unrestricted funds				51,678	30,296
Restricted funds				30,301	24,323
TOTAL FUNDS				81,979	54,619

The financial statements were approved by the Board of Trustees and authorised for issue on 2 July 2022 and were signed on its behalf by:

Mrs V Burford - Trustee

NOTES TO THE FINANCIAL STATEMENTS
for the Year Ended 5 April 2022

1. ACCOUNTING POLICIES**Basis of preparing the financial statements**

The financial statements of the charity, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Charities Act 2011. The financial statements have been prepared under the historical cost convention.

Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Expenditure

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Taxation

The charity is exempt from tax on its charitable activities.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

Hire purchase and leasing commitments

Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions payable to the charity's pension scheme are charged to the Statement of Financial Activities in the period to which they relate.

2. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 5 April 2022 nor for the year ended 5 April 2021.

Trustees' expenses

There were no trustees' expenses paid for the year ended 5 April 2022 nor for the year ended 5 April 2021.

3. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £	Restricted fund £	Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	26,403	24,323	50,726
EXPENDITURE ON			
Charitable activities	18,522	-	18,522
NET INCOME	<u>7,881</u>	<u>24,323</u>	<u>32,204</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
for the Year Ended 5 April 2022

3. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES - continued

	Unrestricted fund £	Restricted fund £	Total funds £
RECONCILIATION OF FUNDS			
Total funds brought forward	22,415	-	22,415
TOTAL FUNDS CARRIED FORWARD	<u>30,296</u>	<u>24,323</u>	<u>54,619</u>

4. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	5.4.22	5.4.21
	£	£
Tax and social security	1,860	-
	<u> </u>	<u> </u>

5. MOVEMENT IN FUNDS

	At 6.4.21 £	Net movement in funds £	At 5.4.22 £
Unrestricted funds			
General fund	30,296	21,382	51,678
Restricted funds			
Research fund	24,323	5,978	30,301
TOTAL FUNDS	<u>54,619</u>	<u>27,360</u>	<u>81,979</u>

Net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	77,703	(56,321)	21,382
Restricted funds			
Research fund	12,777	(6,799)	5,978
TOTAL FUNDS	<u>90,480</u>	<u>(63,120)</u>	<u>27,360</u>

Comparatives for movement in funds

	At 6.4.20 £	Net movement in funds £	At 5.4.21 £
Unrestricted funds			
General fund	22,415	7,881	30,296
Restricted funds			
Research fund	-	24,323	24,323
TOTAL FUNDS	<u>22,415</u>	<u>32,204</u>	<u>54,619</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
for the Year Ended 5 April 2022

5. MOVEMENT IN FUNDS - continued

Comparative net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	26,403	(18,522)	7,881
Restricted funds			
Research fund	24,323	-	24,323
TOTAL FUNDS	<u>50,726</u>	<u>(18,522)</u>	<u>32,204</u>

A current year 12 months and prior year 12 months combined position is as follows:

	At 6.4.20 £	Net movement in funds £	At 5.4.22 £
Unrestricted funds			
General fund	22,415	29,263	51,678
Restricted funds			
Research fund	-	30,301	30,301
TOTAL FUNDS	<u>22,415</u>	<u>59,564</u>	<u>81,979</u>

A current year 12 months and prior year 12 months combined net movement in funds, included in the above are as follows:

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	104,106	(74,843)	29,263
Restricted funds			
Research fund	37,100	(6,799)	30,301
TOTAL FUNDS	<u>141,206</u>	<u>(81,642)</u>	<u>59,564</u>

6. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 5 April 2022.

**NOTES TO THE FINANCIAL STATEMENTS - continued
for the Year Ended 5 April 2022**

7. RESTRICTED FUNDS

The purposes for which the restricted funds are held by the charity are:

Research fund

Funds intended by donors to be used to advance medical and scientific knowledge and understanding of the causes, treatment and management of PANS and PANDAS.

PANS / PANDAS UK

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
for the Year Ended 5 April 2022**

	5.4.22 £	5.4.21 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	90,340	50,488
Merchandise	140	238
	<hr/>	<hr/>
	90,480	50,726
	<hr/>	<hr/>
Total incoming resources	90,480	50,726
	<hr/>	<hr/>
EXPENDITURE		
Other trading activities		
Fund raising	4,582	16,959
Project costs	27,454	-
Exhibitions / Awareness	5,277	1,563
Staff costs	18,164	-
Administration	3,502	-
Professional fees	4,141	-
	<hr/>	<hr/>
	63,120	18,522
	<hr/>	<hr/>
Total resources expended	63,120	18,522
	<hr/>	<hr/>
Net income	27,360	32,204
	<hr/>	<hr/>

Independent examiner's report to the trustees of PANS PANDAS UK

I report on my examination of the accounts of the charity ("the Trust") for the year ended 5th April 2022

Responsibilities of Trustees and Examiner

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 which gives me cause to believe that in, any material respect:

- The accounting records were not kept in accordance with section 130 of the Charities Act; or
- The accounts did not accord with the accounting records; or
- The accounts did not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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.



Steven Mugglestone BA (Hons) FCA
Michael Harwood & Co
Chartered Accountants
Greville House
10 Jury Street
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19 July 2022