



Year ending 5 April 2023

# PANS PANDAS UK

# Annual Report 2022/23

# Introduction

As Chair of PANS PANDAS UK (PPUK), I am pleased to present the Annual Report for 2022-23.



The report describes what PPUK has achieved over the last year, and how our income has been used to further our aims.

Some of the more notable achievements have included the following:

- Gaining better recognition of the conditions PANS and PANDAS within the medical community through the formation of the PANS PANDAS Working Group (PPWG), which consists of representatives from many Royal Colleges and professional medical bodies.
- Ongoing meetings with NHS England and regular meetings of the PANS Physician's Network (PPN);
- Widening our political reach by the development of the new All Party Parliamentary Group (APPG);
- Improved governance by developing the Board of Trustees, developing a new Strategy, enhancing our risk management processes, and developing a Fundraising Plan;
- Pledging Funds for Pilot Research Projects;
- Strengthening our links with families by creating a series of Webinars, Regional Family Gatherings, Online Zoom Meetings, a Customer Relationship Management Package, regular newsletters and increased social media presence;
- Listening to the voice of young people with PANS and PANDAS with the development of the Youth Advisory Board.

One important governance change was the decision to make the post of Chief Executive Officer (CEO) redundant. The CEO functions were distributed more cost-effectively to a combination of volunteers, and a small input from paid staff.

As Chair, I thank the Trustees, our staff, our ambassador and all the volunteers for their invaluable contribution to PPUK, which could not achieve a fraction of the important work undertaken 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 I am so very grateful to them.

Vicky Burford  
Chair of Trustees

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 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.

PPUK 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. PPUK 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, PPUK is providing training for educational professionals so that we 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](http://www.panspandasuk.org)



Absolutely amazing!! Thank you so much to all involved in bringing this to fruition... your commitment and tenacity has finally paid off and you all deserve medals!



Feedback from a community member following the release of the PANS PANDAS Working Group Statement in February 2023

## **Section 2: This Annual Report - General**

This Annual Report for the financial year 2022-23 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 PPUK'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 PPUK's income lies between £25,000 and £250,000, PPUK prepared the accounts on a "Receipts and Payments" basis. This means that the 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. The 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 Principal 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 Chair, 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 of Trustees: Mrs Vicky Burford

Trustee, Treasurer: Mr Philip Edwin Hall

Trustee: Zoe Van Den Bosch

Trustee: Sarah Hughes

Trustee: Diane Palmer

Trustee, Company Secretary: from September 2022: Claire Baggott

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

## **Section 5: Structure, Governance and Management**

### **5.1 The Governing Document**

PPUK has a formal Constitution, which was approved by the Charity Commission on 22 May 2018.

5.2 Our Organisation Chart

The governance and operational structure of PPUK is shown on the organisation chart below.



5.3 Board of Trustees

PPUK is led by the Board of Trustees, as a management committee, with a Chair. The Trustees may be appointed at any time by the management committee. The Board operates by means of trustee meetings, held on a video-conference basis, or physically meeting if necessary. The minutes of the meeting are formally recorded by the Company Secretary.

## 5.4 Our Executive (Operational) Board

In January 2022, PPUK appointed a Chief Executive Officer (CEO) with the aim of enhancing the day-to-day running of the charity. It was expected this would secure substantial new income, more than covering the additional costs involved. The CEO managed the Executive (Operational) Board.

The CEO was appointed in the mutual knowledge that the post would be subject to review. During this reporting year, it became clear to the Trustees that PPUK had been too ambitious in moving to a more fully-staffed organisation, and the financial reserves started to reflect a poorer financial position. PPUK therefore took the step of redundancy, with the CEO's tasks being redistributed among other volunteers, and a much smaller input from paid staff.

There is still an Executive Team (a mix of paid professionals and volunteers) who now report to the Chair of the charity. The Executive Board provides Quarterly Reports to the board of Trustees, describing the actions both completed and planned.

## 5.5 Corporate Governance Standards

In this reporting year, PPUK carried out an assessment of its corporate governance arrangements, against industry-specific best-practice standards. PPUK is strongly committed to further enhancing its corporate governance and risk management framework. There is now a board-approved development plan in place for the next two years to help the charity continue to grow and become more resilient.

## 5.6 Risk Management

During the year, the Trustees started on a path to developing a robust risk management framework for the charity. Work has started on a risk identification and assessment process for greater clarity on the charity's risk profile in the short term. Further developments will be implemented during 2023/2024 to ensure that effective risk management is fully integrated into the charity's strategic and operational activities.

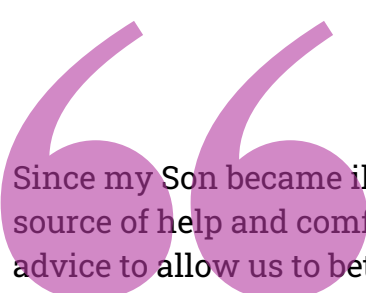
## Section 6: Objectives and Activities

### 6.1 The Purposes of the Charity

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

**1** “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).”

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



Since my Son became ill 3 years ago, PPUK has been a constant source of help and comfort. We have received personal help and advice to allow us to better navigate the difficulty of dealing with the NHS when you have a child who has changed so dramatically almost overnight.

PPUK are changing the landscape in terms of how our children are being treated. They have been successful in securing a priceless change in policy from the BPNA which has meant that my Son is now being offered the kind of support and diagnostic tests which we have been denied for 3 years.

Feedback from a community member after receiving support from PANS PANDAS UK

## 6.2 The Main Activities Undertaken

Some of the more notable achievements over the last year have included the following:

### 6.2.1 Formation of the PANS PANDAS Working Group (PPWG)

This was probably the most important achievement of 2022/23.

Following on from meetings with NHS England and the British Paediatric Neurological Association (BPNA) in 2021/22, a great deal of work was done to develop the PPWG. This group was developed with a view to addressing the misconceptions arising from the BPNA Consensus Statement, to develop a true multi-disciplinary consensus and to work towards developing condition specific treatment pathways, as well as furthering UK-led research opportunities.

This group comprised representatives from the following organisations:

- Royal College of Paediatrics and Child Health;
- Royal College of Psychiatrists;
- Royal College of Nursing;
- Royal College of Occupational Therapists;
- Royal College of General Practitioners;
- British Paediatric Neurological Association;
- British Paediatric Allergy, Immunity and Infectious Diseases Group;
- British Association of Social Workers;
- Representation from Designated Clinical Officers;
- Representation from treating medical professionals.

### 6.2.2 PPWG Statement

One of the key outputs from the PPWG was the release of the PPWG Interim Statement which was written to address the difficulties being caused by the BPNA Consensus Statement. This important statement was written in collaboration with the members of the PPWG and was disseminated by all parties therein. This statement has been well received by health professionals and the PANS community.

### 6.2.3 James Lind Alliance Research Priority Settings for paediatric neurological conditions success

PPUK was represented by the parent of a young child with PANDAS and the Chair of the charity at the priority settings workshop. PPUK was delighted that the question 'Are medications (e.g. antibiotics, and or immune treatments) effective in the management of PANS and PANDAS?)' was voted as the 8th highest priority for paediatric neurological research. PPUK sincerely hopes that this particular question, which is of great importance to the PPUK community, catches the interest of a university.

### 6.2.4 Preparations for new All Party Parliamentary Group (APPG)

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.

### 6.2.5 PANS Physician's Network (PPN) Meetings

The PPN met virtually on a quarterly basis. The meetings were educational and informative. They offered a great opportunity for health professionals with an interest to hear from and meet expert doctors in the field. Each meeting had an expert guest speaker and a case study for discussion, as well as updates in research and other items of interest. These meetings were well attended.

### 6.2.6 Research Roundups

Monthly reviews of research were undertaken by a small group of volunteers and these round-ups were shared with our community, as well as some interested medical professionals. These important round-ups kept everyone up to date with latest research and developments in all medical and scientific fields relating to PANS and PANDAS.

### 6.2.7 Board of Trustees Development

The skill set of the Board of Trustees grew stronger with three new trustees appointed. The Board now benefits from Governance and Risk expertise, Clinical expertise and Research and Data expertise. PPUK is delighted to have these trustees on board and look forward to a long and successful relationship making the charity stronger and more resilient in order to support its community better.

### 6.2.8 Building the Team


Until this reporting year, PPUK was run entirely by volunteers, and, this year, PPUK was strengthened by the appointment of four part-time members of staff to undertake some of the key work being done. PPUK has a strong and committed team of staff and ensuring their wellbeing and personal development is a priority to the Charity.

### 6.2.9 Developed a New Strategy

Much work was put into the development of a new strategy for PPUK, which will be published in a new strategy document in the next financial year.

### 6.2.10 Annual General Meeting (AGM)

The AGM was held in July 2022 via Zoom and the Trustees of PPUK were joined by 39 individuals from the community. Nurse Practitioner and PANDAS expert Amy Joy Fishman Smith from California 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 and recorded.



Absolutely brilliant. Thanks to all for working so hard to bring change x

Feedback from a community member following the release of the PANS PANDAS Working Group Statement in February 2023

### 6.2.11 Pledged Funds for Pilot Research Projects

In 2022-23, PPUK pledged £5,000 to a small UK-led research project with Oxford University to undertake a 'deep-dive' into the micro-organisms of a patient with PANS.

### 6.2.12 Webinar Series

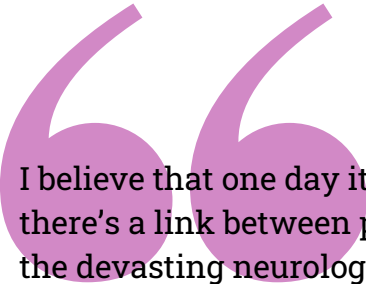
A series of useful and informative expert led webinars were developed for the PPUK community. The majority of these webinars are now available on the website and available for those who were unable to attend the sessions live.

### 6.2.13 In Person Family Meetings

Prior to the Covid-19 pandemic and subsequent lockdown, PPUK used to hold regular regional in-person get-togethers for parents to enable them to feel connected and to have the opportunity to talk to other people in similar circumstances. This was stopped due to the pandemic, but these have now started to take place in-person, again with good engagement from the community.

### 6.2.14 Fortnightly Zoom Meetings

PPUK held a volunteer-led Zoom meeting every fortnight for parents who are unable to attend face to face get togethers. These zoom meetings helped people to feel less isolated and part of the community.



I believe that one day it will be commonly accepted that there's a link between post infection inflammation and the devastating neurological damage that this can cause. If we are to get there soon, then it will be down to the dedication of this amazing charity and its inspirational team.

Feedback from a community member after receiving support from PANS PANDAS UK

### 6.2.15 Facebook Support Group for Adults with PANS

The Board took the decision, during this financial year, to hand over the management of the Adults with PANS Facebook Support Group to the European counterparts EXPAND. There were a number of reasons for this:

- Due to an increased demand for support by adults throughout Europe, it was felt that it would be better managed by an organisation with the ability to navigate the various European health systems.
- Capacity restraints within the team.
- The belief that the only way to make a lasting difference for adults is to focus on improving acceptance and developing management of the conditions for children. Once this has been done, this will pave the way for understanding of the conditions in adults.

### 6.2.16 Teacher Training (CPD Accredited)

The CPD-Accredited live Teacher Training webinars have proved very popular with 12 sessions delivered. Approximately 285 educators have benefitted from the training during this financial year. Work is being done on developing these sessions for a wider audience, including Educational Psychologists, SEND professionals, Designated Clinical Officers and Universities.

### 6.2.17 Development of Resources

In the last financial year, PPUK developed a number of new resources to support our community, and professionals. A new website is under development with a planned launch in the summer of 2023.

### 6.2.18 Development of a Fundraising Plan

In 2022, PPUK appointed a dedicated part-time fundraiser who launched PANS PANDAS UK's very first charity led fundraiser, Walk4. A comprehensive fundraising plan was developed for 2023/24 which included more community fundraising events and applications for grants as well as recruiting a number of corporate sponsors.

### 6.2.19 Customer Relationship Management (CRM) Package

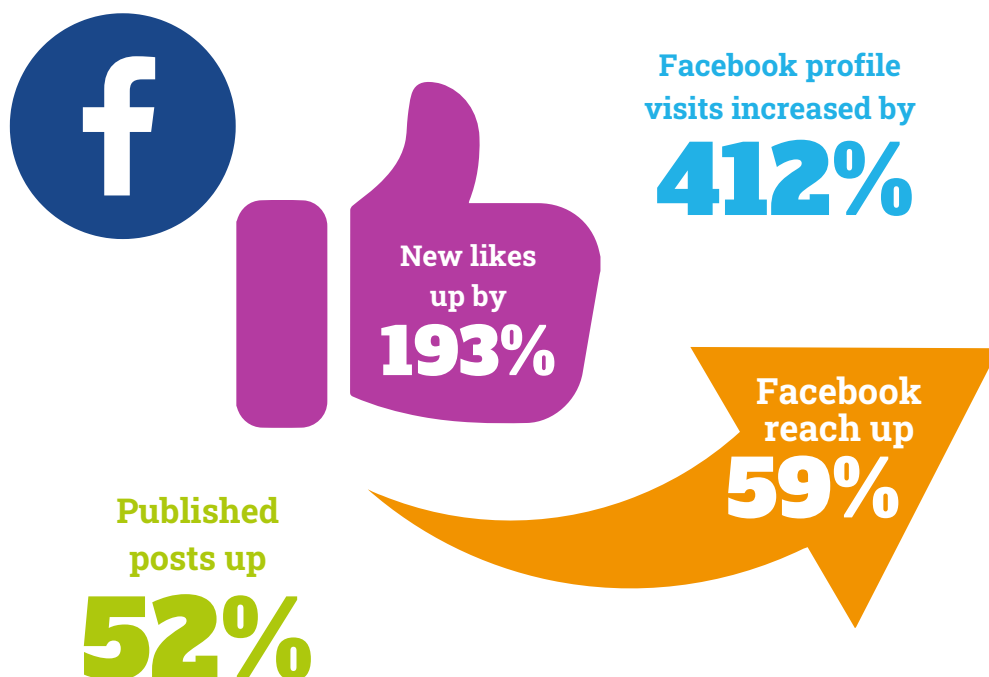
As part of the fundraising plan, PPUK installed 'Donorfy' (a fundraising CRM programme) which helped to more effectively manage fundraising campaign record-keeping and enable a better stewardship of donors and fundraisers going forward.

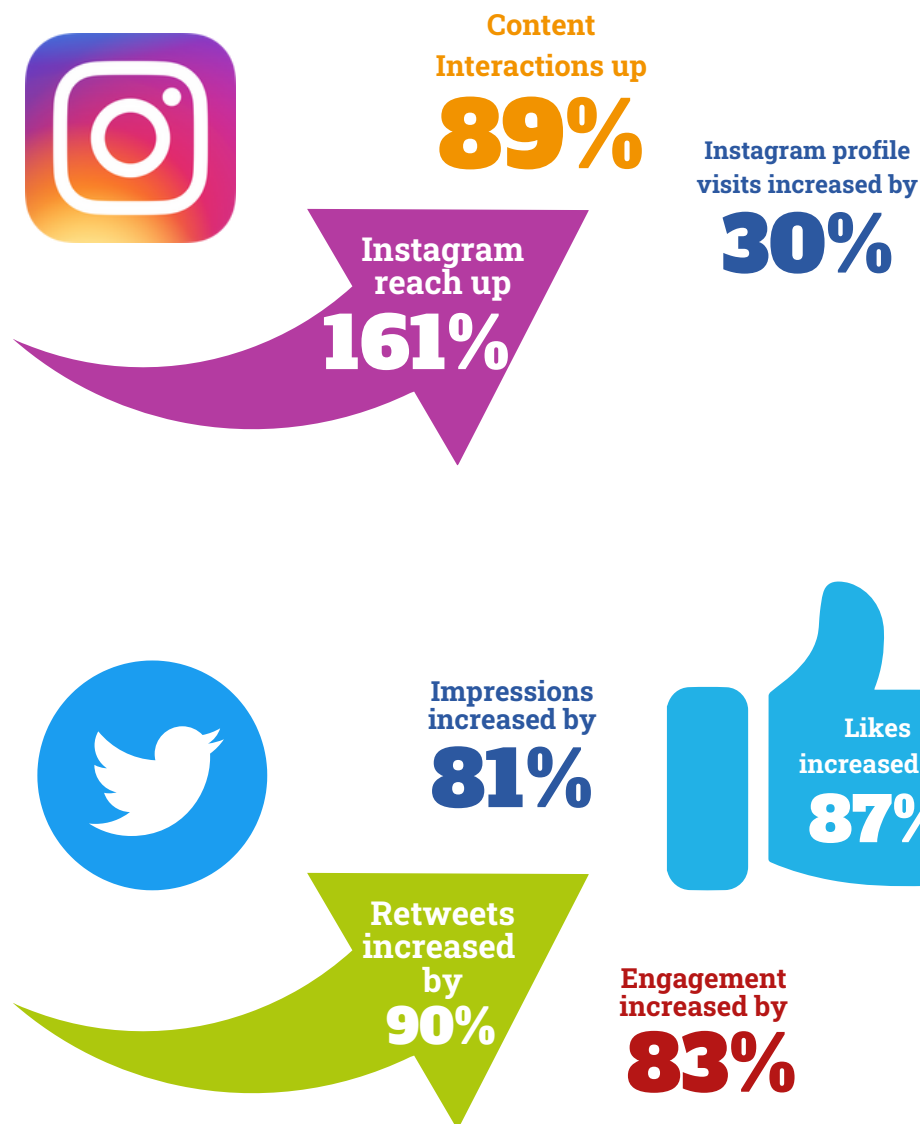
### 6.2.20 Safeguarding Survey

PPUK carried out a survey of our community with a focus on safeguarding. This survey was undertaken because of a need to understand the impact of the disproportionate number safeguarding or 'Fabricated or Induced Illness' referrals raised due to the 'perplexing presentations' nature of the constellation of PANS and PANDAS symptoms.

### 6.2.21 Social Media Presence

We increased our social media presence during 2022/23





### 6.2.22 Youth Advisory Board

The PANS PANDAS UK Youth Advisory Board was launched in September 2022. The Board is made up of fourteen members aged between 8 and 20. Meetings are held every 8 weeks.

The purpose of the Youth Board is to more fully integrate young people affected by PANS and PANDAS into PPUK's activities, ensuring that their voice and experience inform and shape our mission. The knowledge and enthusiasm members bring to the Board is inspiring and, in return, members experience a sense of community and are able to contribute towards meaningful change for other young people with the conditions. There is so much potential for future joint initiatives, particularly within the areas of fundraising, resource writing and raising awareness.

## Section 7: Achievements and Performance

### 7.1 Our Main Mission

PPUK exists to serve the community affected by PANS or PANDAS, recognising that the community is made up of various groups based on common experiences. Everything PPUK does is based on assessment of our community's wants and needs which in turn supports our direction and purpose.

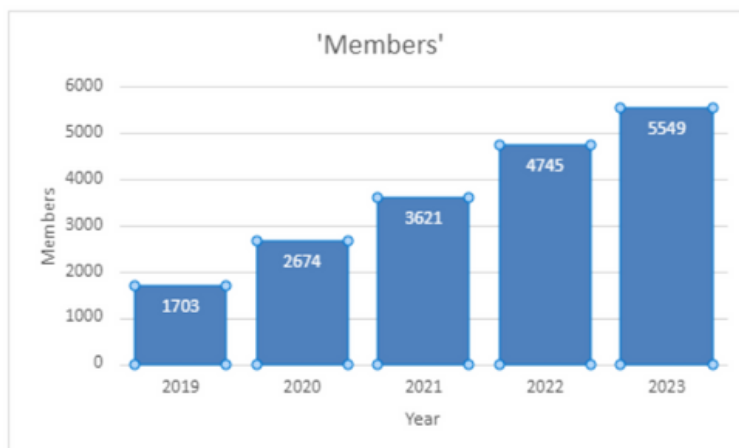
PPUK's mission to promote understanding and awareness of PANS and PANDAS in order to support the health and wellbeing of everyone impacted by these conditions in the UK.

PPUK:

- provides information and resources to help inform and support families and individuals about diagnosis of PANS and PANDAS, healthcare, managing symptoms and educational support;
- builds relationships with healthcare, education and social care professionals to increase understanding, empathy and support of those affected by PANS and PANDAS;
- strives for systemic change to ensure excellent, effective and equitable treatment for everyone affected by PANS or PANDAS.

### 7.2 "Members"

PPUK does not have a formal membership scheme in place and so the measure of our "members" is measured by the Facebook support group. There has been a steady growth in numbers joining the Facebook support group year on year.



### 7.3 Service User Feedback

Here is a selection of some of the comments PPUK has received from it's community members.


"Thank you so much for everything you do. Angels the lot of you. So thankful; you guys never give up x"

"Sending lots of appreciation to you and the charity which has saved my girl."

"Well done PANS PANDAS UK, you are an amazing charity"

"Thanks so much for your support to get us this far, I'll never ever forget how you helped me in the darkest of times."

"Thank you for pushing this! I look forward to the day when you can go to your doctor with the symptoms and they know exactly what to do to help you and your child. Great step forward!"

"No more living in fear, being treated like criminals for doing what's right for your child! PANDAS UK I have nothing left to moan about; I'm just so happy and relieved for every parent and child!!!  This charity deserves OBE's all round!!!"

"Thank you! You have made one very stressed and worried parent (actually many grown-ups in our family) much less stressed."

"What amazing, wonderful, hardworking people you all are. Thankyou xxx"

"Oh Wow!!! Thank you Team PP. You are all amazing. This is a massive accomplishment. Thank you on behalf of our children and future children"

## Section 8: Financial Review

### 8.1 The Reporting Period for this Report

PPUK's financial performance reported below is for the period from 6 April 2022 to 5 April 2023. During this period, PPUK moved away from a spreadsheet approach, and adopted a software package called Xero to manage and monitor the financial transactions. This did not have any implication in terms of reporting, but Xero is a piece of software more compatible with HMRC requirements and is more familiar to PPUK's Auditors.

### 8.2 Our Accounts and Bankers

PPUK operates using two bank accounts, as follows:

- Santander Business Account
- Unity Trust Bank Business Account

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

The tables below present the financial results for the financial year 2022/23.

Table 8.3.1 gives a breakdown of the Charity's income.

TABLE 8.3.1 : Income Breakdown		
Source of Income	Amount (Rounded)	%
Trusts and Foundations	£4,000	5%
Event (community led) income	£26,443	35%
Corporate or organisational donations	£10,885	14%
Donations from individuals	£21,012	27%
Gift Aid	£9,639	13%
Regular Giving	£3,269	4%
Balance – Smaller Items	£1,077	1%
Total Income (Exact)	£76,325.81	100%

Table 8.3.2 presents a summary of the expenditure of the charity.

TABLE 8.3.2: Expenditure Breakdown		
Allocation of Expenditure	Amount (Rounded)	%
Health Development Programme	£23,186	19.3%
Education Development Programme	£22,899	19.1%
Patient Information and Support	£30,727	25.5%
Research	£5,000	4.2%
Cost of Generating Funds	£21,025	17.5%
Governance	£17,198	14.3%
Total Expenditure (Exact)	£120,034.98	100%

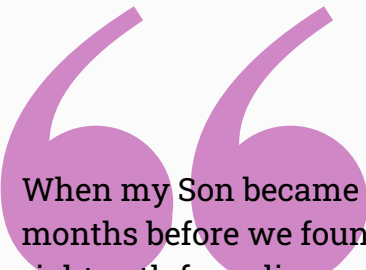
Table 8.3.3 presents the profit / loss on the year.

TABLE 8.3.3 Profit / Loss on the year	
	Amount
Total Income	£76,325.81
Total Expenditure	£120,034.98
Total Profit (Loss)	(£43,709.17)

Table 8.3.4 presents the assets / liabilities held as at 5th April 2023, and the amounts held in restricted and unrestricted funds.

TABLE 8.3.4 Assets / Liabilities held as at April 5th, 2023	
	Amount
Brought Forward - Assets held at April 5th 2022	£81,978.37
Surplus / (Deficit) on Financial Year 2022/23	(£43,709.17)
Current Total Assets (Liabilities)	£38,269.20
Held in Unrestricted Funds	£12,968.35
Held in Restricted Funds	£25,300.85

The charity's financial position and accounts have been subjected to independent verification. The examiner's report states that there were no matters of concern. The verification report, and the full set of statutory accounts, are available for inspection on the Charity Commission website.



When my Son became so ill so suddenly, it took us 12 months before we found PPUK which then put us on the right path for a diagnosis. PPUK are working hard within healthcare, education, and government in order to improve knowledge and awareness of this truly awful illness. It is essential that awareness of PP is built in all settings dealing with children, as this is the only way to prevent children suffering for longer than they need to.

Feedback from a community member after receiving support from PANS PANDAS UK

## 8.4 Policies on Reserves

PPUK has started to develop a more formal risk-based approach to the level of reserves held, in both restricted and unrestricted funds. This work will continue into 2023/24.

Future Annual Reports will formally report the reserves policy, and the amounts held. It is likely that PPUK will seek to maximise the holdings in unrestricted funds. The analysis will describe an absolute minimum of reserves to reflect our contractual arrangements and will also demonstrate a more substantial reserves position to allow PPUK to continue charitable activities if faced by exposure to a loss of promised income.

## 8.5 Funds in Deficit

PPUK does not have any funds in deficit.

## 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

It is PPUK's belief that the charity has 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, the following text provide headlines for planned activity in the financial year 2023/24.

### 11.1 All Party Parliamentary Group (APPG)

Plans are in motion to reconvene the APPG. This APPG has the objective of using political influence (from members of parliament across all political parties) to improve the detection, diagnosis and provision of treatment for PANS and PANDAS in the UK. Following the recent Early Day Motion and subsequent questions raised in parliament, PPUK looks forward to working with MPs and our community to achieve our objective.

### 11.2 PANS PANDAS Working Group

A key part of the PANS PANDAS Working Group plan is to create three 'task and finish groups' each with their own focus. These task forces will be named as follows:

- Surveillance Study and Research Group. Chaired by Professor Alastair Sutcliffe, this task force will make an application to undertake a Surveillance Study and investigate research opportunities.
- Consensus/Guideline Development Group. Chaired by an independent doctor, yet to be appointed, this task force will work with key stakeholders to develop a true consensus regarding management of the conditions and develop a set of guidelines for adoption by the NHS.
- Pathway/Service Specification Group. Chaired by Diane Palmer, Associate Director of Nursing NSFT and Trustee of PANS PANDAS UK, this task force will work to develop a pathway for those affected by PANS or PANDAS.

### 11.3 Launch of new website

The new PPUK website will be launched in the summer of 2023, with a more personal look, a clearer focus and more accessible resources.

### 11.4 Patient Information Review

During 2023/24, PPUK plans to undertake a review of the existing patient information resources and develop additional resources in line with what our community have said they would like to see.

### **11.5 Building relationships with international counterparts**

As a member of the board of EXPAND (the European umbrella organisation representing all patient communities within Europe), PPUK has good relationships with European counterparts, but in 2023/24, the aim is to reach out to the wider International PANS peers and work together to develop PANS and PANDAS acceptance worldwide.

### **11.6 Challenge Community Fundraising Campaign**

As part of the new fundraising plan, PPUK created an annual Fundraising Campaign called the @ChooseYourChallenge fundraising campaign. Considerable community support is expected for this campaign, as well as companies from the Birmingham Chamber of Commerce, and other supporters to make this a successful fundraiser which will become a legacy event for PANS PANDAS UK.

### **11.7 Youth Advisory Board led Family Fun Day**

Following the development of the PANS PANDAS UK Youth Advisory Board, the members have expressed a desire to meet other young people with PANS and PANDAS and have suggested a community picnic in the summer. The members would like this to be in the form of a summer fete, with stalls and some entertainment. Work is currently underway to make this happen in line with the Youth Board preferences.

### **11.8 Volunteer Strategy**

PPUK benefits from a large and engaged community with many volunteering opportunities. PPUK hopes to develop a volunteer strategy during 2023/24 to utilise the skills of these volunteers.

### **11.9 Investigate a Membership Scheme**

Currently, PPUK does not have a formal membership scheme, counting the members of the Facebook support group as 'membership', although this is neither accurate nor ideal. PPUK will investigate the development of a membership scheme during the course of 2023/24, to enable a better understanding of "our community" and identify more accurately how many people are supported.

### 11.10 Disseminate Condition Information and Awareness to Schools

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

### 11.11 Safeguarding and FII Guide for Professionals

Following on from the results of the safeguarding survey which was undertaken in January 2023, a PANS PANDAS Safeguarding and FII guide for health, social work and education professionals is being written in collaboration with an independent Social Worker. It is our intention that this guide will be published during FII Week in May 2023.

## 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 2022 to 5th April 2023.

Signed:



Name: Vicky Burford

Position: Chair of Trustees, PANS PANDAS UK

Date: 19th October 2023

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 2023  
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 2023**

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## **PANS / PANDAS UK**

### **REPORT OF THE TRUSTEES for the Year Ended 5 April 2023**

The trustees present their report with the financial statements of the charity for the year ended 5 April 2023. 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](http://www.panspandasuk.org)

#### **STRUCTURE, GOVERNANCE AND MANAGEMENT**

##### **Governing document**

The charity is controlled by its governing document, being constituted as a Charitable Incorporated Organisation (CIO), registered charity number 1178484.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

##### **Registered Charity number**

1178484

##### **Principal address**

Greville House  
10 Jury Street  
Warwick  
Warwickshire  
CV34 4EW

##### **Trustees**

Mrs V Burford  
Mr P Hall  
Ms Z Van Den Bosch  
Ms S Hughes (appointed 27.4.22) (resigned 15.6.23)  
Ms D Palmer (appointed 26.4.22)  
Miss C D Baggott (appointed 9.9.22)

##### **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 29 August 2023 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 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 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

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

Date: 20<sup>th</sup> October 2023

PANS / PANDAS UK

STATEMENT OF FINANCIAL ACTIVITIES  
for the Year Ended 5 April 2023

	Notes	Unrestricted fund £	Restricted funds £	5.4.23 Total funds £	5.4.22 Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>					
Donations and legacies		<u>72,324</u>	<u>4,000</u>	<u>76,324</u>	<u>90,480</u>
<b>EXPENDITURE ON</b>					
Health development programme		23,186	-	23,186	
Education development programme		18,899	4,000	22,899	
Patient information and support		30,727	-	30,727	
Research		-	5,000	5,000	
<b>Total charitable activities</b>		<b>81,812</b>		<b>81,812</b>	54,646
<b>Cost of generating funds</b>		<b>21,025</b>		<b>21,025</b>	
<b>Governance</b>		<b>17,198</b>		<b>17,198</b>	8,474
		<hr/>	<hr/>	<hr/>	<hr/>
<b>Total</b>		<u>111,035</u>	<u>9,000</u>	<u>120,035</u>	<u>63,120</u>
<b>NET INCOME/(EXPENDITURE)</b>	5	<b>(38,711)</b>	<b>(5,000)</b>	<b>(43,711)</b>	27,360
<b>RECONCILIATION OF FUNDS</b>					
Total funds brought forward		<u>51,678</u>	<u>30,301</u>	<u>81,979</u>	<u>54,619</u>
<b>TOTAL FUNDS CARRIED FORWARD</b>	5	<u><u>12,967</u></u>	<u><u>25,301</u></u>	<u><u>38,268</u></u>	<u><u>81,979</u></u>

The notes form part of these financial statements

**PANS / PANDAS UK**

**BALANCE SHEET**  
**5 April 2023**

	Notes	Unrestricted fund £	Restricted funds £	<b>5.4.23 Total funds £</b>	<b>5.4.22 Total funds £</b>
<b>CURRENT ASSETS</b>					
Debtors	4	-	-	-	1,860
Cash at bank		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>80,119</u>
		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
<b>NET CURRENT ASSETS</b>		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
<b>TOTAL ASSETS LESS CURRENT LIABILITIES</b>		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
<b>NET ASSETS</b>		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
<b>FUNDS</b>	5				
Unrestricted funds				<u>12,967</u>	51,678
Restricted funds				<u>25,301</u>	<u>30,301</u>
<b>TOTAL FUNDS</b>				<u>38,268</u>	<u>81,979</u>

The financial statements were approved by the Board of Trustees and authorised for issue on 19 October 2023 and were signed on its behalf by:

Mrs V Burford - Trustee

**NOTES TO THE FINANCIAL STATEMENTS**  
**for the Year Ended 5 April 2023**

**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 2023 nor for the year ended 5 April 2022.

**NOTES TO THE FINANCIAL STATEMENTS - continued**  
**for the Year Ended 5 April 2023**

**2. TRUSTEES' REMUNERATION AND BENEFITS - continued****Trustees' expenses**

For the year ended 5th April 2023 the following expenses were reimbursed to trustees:

Travel - £2,138.21

Printing, postage and stationery - £70.96

Total - £2,209.17

**3. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES**

	Unrestricted fund £	Restricted funds £	Total funds £
<b>INCOME AND ENDOWMENTS FROM</b>			
Donations and legacies	<u>77,703</u>	<u>12,777</u>	<u>90,480</u>
 <b>EXPENDITURE ON</b>			
Charitable activities	47,847	6,799	54,646
<b>Charitable activities</b>			
Governance	<u>8,474</u>	<u>-</u>	<u>8,474</u>
<b>Total</b>	<u>56,321</u>	<u>6,799</u>	<u>63,120</u>
 <b>NET INCOME</b>	21,382	5,978	27,360
 <b>RECONCILIATION OF FUNDS</b>			
Total funds brought forward	<u>30,296</u>	<u>24,323</u>	<u>54,619</u>
 <b>TOTAL FUNDS CARRIED FORWARD</b>	<u>51,678</u>	<u>30,301</u>	<u>81,979</u>

**4. DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR**

	5.4.23 £	5.4.22 £
Tax and social security	<u>-</u>	<u>1,860</u>

**5. MOVEMENT IN FUNDS**

THIS PERIOD 2022-23	Funds at 6.4.22 £	Incoming resources	Expended resources	Net movement in funds	Funds at 5.4.23 £
Unrestricted (General) fund	51,678	72,324	(111,035)	(38,711)	12,967
Education Fund	-	4,000	(4,000)	-	-
Research Fund	30,301	-	(5,000)	(5,000)	25,301
<b>TOTAL FUNDS</b>	<u>81,979</u>	<u>76,324</u>	<u>(120,035)</u>	<u>(43,711)</u>	<u>38,268</u>

PANS / PANDAS UK

NOTES TO THE FINANCIAL STATEMENTS - continued  
for the Year Ended 5 April 2023

5. MOVEMENT IN FUNDS - continued

<b>COMPARATIVE FOR PREVIOUS PERIOD 2021-22</b>	<b>Funds at 6.4.21 £</b>	<b>Incoming resources</b>	<b>Expended resources</b>	<b>Net movement in funds</b>	<b>Funds at 5.4.22 £</b>
<i>Unrestricted (General) fund</i>	30,296	77,703	(56,321)	21,382	51,678
<i>Education Fund (did not exist)</i>	-	-	-	-	-
<i>Research Fund</i>	24,323	12,777	(6,799)	5,978	30,301
<b>TOTAL FUNDS</b>	<b>54,619</b>	<b>90,480</b>	<b>(63,120)</b>	<b>27,360</b>	<b>81,979</b>

6. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 5 April 2023.

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 2023

	5.4.23 £	5.4.22 £
<b>INCOME AND ENDOWMENTS</b>		
<b>Donations and legacies</b>		
Donations	76,238	90,340
Merchandise	<u>86</u>	<u>140</u>
	<b>76,324</b>	<b>90,480</b>
<b>Total incoming resources</b>	<b>76,324</b>	<b>90,480</b>
<b>EXPENDITURE</b>		
<b>Charitable activities</b>		
Project costs	22,022	27,454
Exhibitions / Awareness	-	2,639
Project worker costs	52,366	12,715
Administration	4,156	2,101
Communications	<u>3,269</u>	<u>-</u>
	<b>81,813</b>	<b>44,909</b>
<b>Support costs</b>		
<b>Cost of generating funds</b>		
Project worker costs	6,260	1,816
Communications	1,090	2,639
Fundraising	13,121	4,582
Admin costs	<u>554</u>	<u>700</u>
	<b>21,025</b>	<b>9,737</b>
<b>Governance costs</b>		
Staff costs	8,689	3,633
Admin costs	831	700
Governance costs	<u>7,677</u>	<u>4,141</u>
	<b>17,197</b>	<b>8,474</b>
<b>Total resources expended</b>	<b>120,035</b>	<b>63,120</b>
<b>Net (expenditure)/income</b>	<b><u>(43,711)</u></b>	<b><u>27,360</u></b>

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

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

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Steven Mugglestone

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

Date: 20<sup>th</sup> October 2023