

PANS/PANDAS UK

England & Wales · Charity number 1178484

Details

Status Registered

Legal form CIO

Registered 2018-05-22

Register [View on the Charity Commission register](#)

Contact

Address Greville House
10 Jury Street
Warwick
Warwickshire
CV34 4EW

Phone 07808764750

Email info@panspandasuk.org

Website www.panspandasuk.org

Activities

Objects: 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). To relieve the need of sufferers (and families) of the medical conditions PANS and PANDAS by the provision of support, education, and practical advice.

Activities: PANS PANDAS UK is the only UK charity supporting children and families living with these conditions. We provide information, advocacy and community support to patients and carers. We raise awareness of the symptoms and treatment options for healthcare, educational and social work professionals so that they are better equipped to recognise when a child may have PANS or PANDAS.

Classification

- **How:** Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Other Charitable Activities
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Other Charitable Purposes
- **Who:** Children/young People, Other Defined Groups, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£159,413	£149,242	-	-
2024-04-05	£145,355	£106,587	-	-
2023-04-05	£76,326	£120,035	-	-
2022-04-05	£90,480	£63,120	-	-
2021-04-05	£50,727	£18,522	-	-

Trustees

Name	Role	Appointed
Andrew Robert Koss	Chair	2025-06-01
Christopher Mark Derrer		2024-05-31
Philip Edwin Hall		2018-06-30
Victoria Queralt		2024-10-12

Accounts

Year ending 31st March 2025

PANS PANDAS UK

Annual Report

2024/25



Introduction

I am pleased to present this Annual Report for 2024-25, which as usual describes what the charity has achieved over the last year, and how our income has been used to further our objectives. We have made some great strides this year, and it is my pleasure to outline some of these achievements in this report.

We may be a small team, but we are a powerful one, and before sharing the progress we've made, I want to take a moment to recognise the incredible people behind it all.

First, my heartfelt thanks go to our Board of Trustees, whose unwavering commitment ensures that PANS PANDAS UK remains a well-governed and forward-thinking organisation. I'm continually inspired by our dedicated staff team, whose passion and perseverance drive our mission forward. It's truly a privilege to work alongside such talented and compassionate individuals.

I also want to extend sincere appreciation to our amazing volunteers. Your contributions are invaluable. Whether you've taken on a fundraising challenge, made a donation, shared a post, contacted your MP, or handed a leaflet to your GP. Every action you have taken has made a difference. The awareness raised and the support we receive are thanks to your efforts, and I am deeply grateful. We are acutely aware of the ongoing cost-of-living crisis and the additional pressures it places on our community. Your continued support during these challenging times is deeply appreciated and never taken for granted.

While you'll find a full overview of our key achievements later in this report, I'd like to highlight a few milestones that stand out.



Our collaboration with the PANS PANDAS Steering Group has been particularly impactful, with significant progress made toward developing clinical guidelines in partnership with the Royal College of Paediatrics and Child Health (RCPCH). We're also proud to support the first NHS-led research into PANS and PANDAS through a national surveillance study, which is an important step forward for recognition and understanding of these conditions.

This year also saw the launch of a CPD-accredited GP training module. The uptake has exceeded expectations, clearly demonstrating the demand for education in this area and reinforcing the importance of our ongoing work to support clinical guideline development.

Our teacher training programme continues to grow from strength to strength, now being delivered across the UK. We're also expanding this work to include tailored training for Educational Psychologists, further helping to ensure that children affected by PANS and PANDAS are better supported in educational settings.

Our Youth Board has been incredibly active,

leading the way with our 2024 Awareness Day campaign, Ask the Experts. This was the first youth-led initiative of its kind internationally, and we're excited to build on its success by involving even more professionals and young people themselves, as experts by experience in answering questions from our young people.

We're also expanding our network of in-person support groups, led by our wonderful volunteers. These groups offer vital opportunities for connection and community, helping to combat the isolation that so many families experience. Alongside this, we've launched our Friends of PANS PANDAS UK programme, giving us a clearer picture of the community we represent and reminding us that we are indeed stronger together.

Finally, I'd like to share some personal news. In June 2025, I stepped down as Chair of the Board after 7 years as a trustee, to take on the new role of Chief Executive Officer of PANS PANDAS UK.

I'm thrilled to be able to dedicate myself fully to the charity in this capacity and to continue championing the needs of the PANS PANDAS community across the UK.

I'm also pleased that we were able to announce that an existing Trustee, Andrew Koss, will be taking over as Chair. With his significant experience and commitment, I have every confidence that the governance of the organisation will remain as robust as ever.

Warmest regards,



Vicky Burford
Chief Executive Officer, formerly Chair of Trustees



PANS PANDAS UK have been so incredibly supportive to us as a family, without them and the PANS PANDAS UK community I don't know if we would have made it through this hell. This condition is like no other and is often mis-diagnosed leaving children disabled unable to leave the house and with no support or treatment options available on the NHS.

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

[Section 4:](#) Reference and Administrative Details

[Section 5:](#) Structure, Governance and Management

[Section 6:](#) Objectives and Activities

[Section 7:](#) Achievements and Performance

[Section 8:](#) Financial Review

[Section 9:](#) Funds Held as Custodian Trustee on Behalf of Others

[Section 10:](#) Public Benefit Statement

[Section 11:](#) Plans for Future Periods

[Section 12:](#) Signed Statement

[Section 13:](#) Appendices

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 Obsessive-Compulsive Disorder (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) operates nationally across the UK and was granted charity status in England and Wales on 22 May 2018 and then in Scotland on 20 March 2024. PPUK has 7 part time employees (3.03 FTE) and utilises the experience of three independent contractors.

Please visit our website for more information:

www.panspandasuk.org



PANS PANDAS UK was a lifeline of hope for my family when our daughter suddenly fell unwell with this condition. This charity work tirelessly to raise awareness and support families and young people affected by the devastating condition.

Section 2: This Annual Report - General

This Annual Report for the financial year 2024-25 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 we anticipate our income rising in future to above £250k, we have prepared our accounts on an accruals 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

PANS PANDAS UK is registered with the Charity Commission for England and Wales: 1178484 and the OCSR in Scotland: SC053206

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 in 2024/25 was through the then Chair of Trustees, Mrs Vicky Burford, who can be contacted at vicky.burford@panspandasuk.org or via the Charity's registered office below.

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

4.4 Names of Charity's Trustees

[Mrs Vicky Burford](#): resigned as [Chair of Trustees](#) on 2 June 2025

[Mr Philip Edwin Hall](#): Treasurer

[Mr Andrew Koss](#): appointed trustee 31 May 2024

appointed to [Chair of Trustees](#) 2 June 2025

[Mr Chris Derrer](#): appointed trustee 31 May 2024

[Ms Rebecca Huitson](#): appointed trustee 31 May 2024, resigned 18 April 2025

[Mrs Victoria Queralt](#): appointed trustee 12 October 2024

[Diane Palmer](#): resigned 30 August 2024

No other people served as a charity trustee or custodian trustee between 1 April 2024 and 31 October 2025.

Section 5: Structure, Governance and Management

5.1 The Governing Document

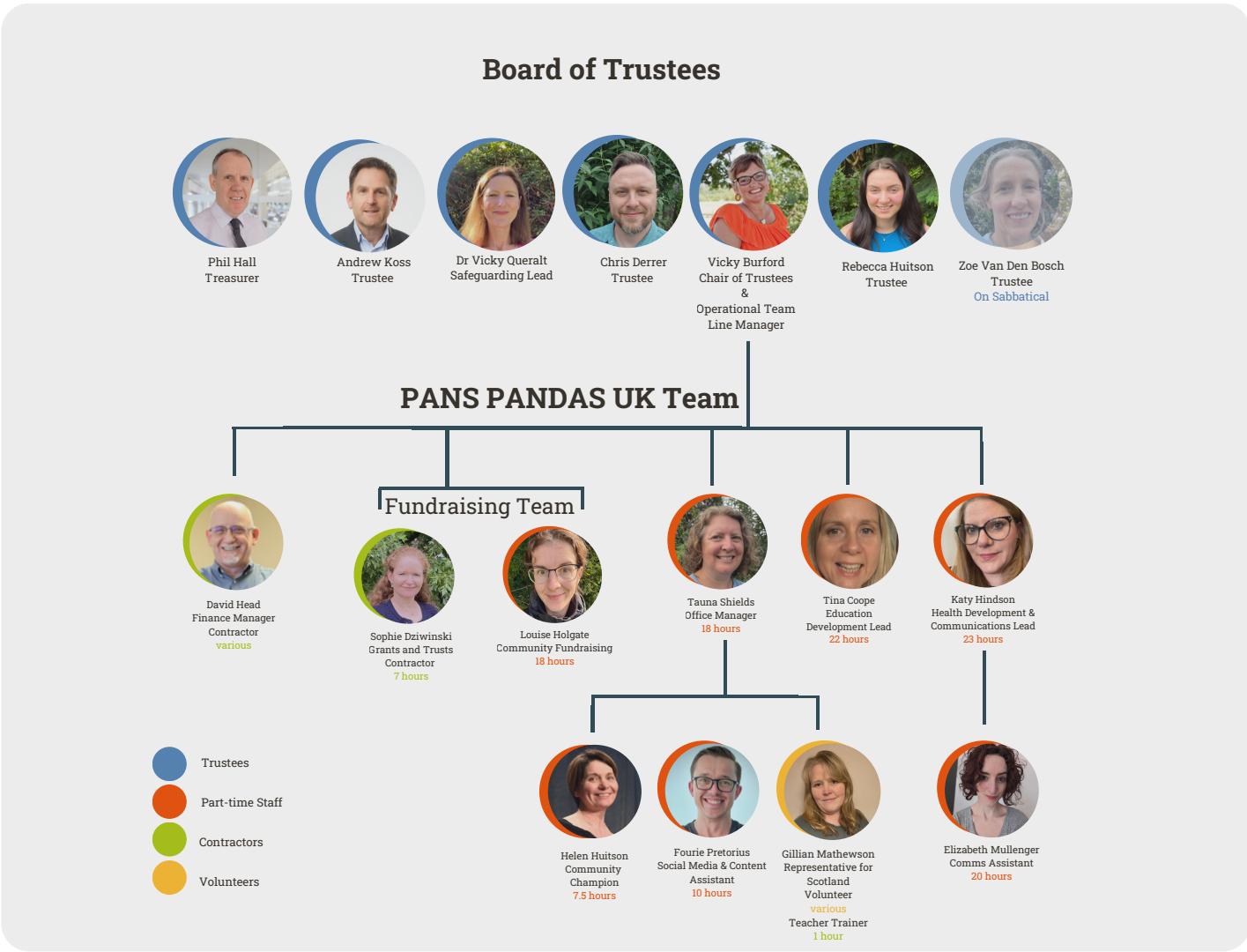
The Charity has a formal Constitution, the founding one being approved by the Charity Commission on 22 May 2018. A review of the Constitution was made by the Trustees in early 2024 with a view to simplifying the document and clarifying our charitable objects.

The Charity is governed by the Board of Trustees which meets via video-conference once per quarter. Minutes are formally recorded following each board meeting. Trustees may be appointed at any time by the Board of Trustees.

The Charity benefits from 7 part-time employees and utilises the expertise of 3 contracted staff to undertake the day to day running of operations.

5.2 Our Organisation Chart

The governance and operational structure of PPUK for the year ending 5th April 2024 is shown on the organisation chart below.



5.3 Board of Trustees

PPUK is led by the Board of Trustees with a Chair. Trustees may be appointed at any time by the Board. The Board operates by means of trustee meetings, held on a video-conference basis, or physically meeting if necessary.

5.4 Our Operational Team

The work of the charity is carried out by an operational team. As at the end of the financial year, the charity currently has 7 employed staff all working on a part time basis.

Alongside the employed staff, the charity is supported by 3 contracted staff members, Finance Manager, Grants and Trusts Manager and Teacher Trainer.

The total part time hours worked are equivalent to 3.03 full time employees.

The work of the team is also supported by some excellent and committed volunteers.

5.5 Corporate Governance Standards

In this reporting year, PPUK continued developing its corporate governance framework following the board approved plan set out during 2022/23 to ensure that we follow industry-specific best practice standards.

As part of this PPUK is strongly committed to further enhancing its risk management framework, with work actively being undertaken to mitigate risk and help the charity continue to grow and become more resilient.

5.6 Risk Management

Following the implementation of a robust risk management framework for the charity during the previous reporting year, work on a risk identification and assessment process for greater clarity on the charity's risk profile continues. Further developments will be implemented during 2025/2026 to ensure that effective risk management remains fully integrated into the charity's strategic and operational activities.

Section 6: Objectives and Activities

6.1 The Purposes of the Charity

The charity's purposes concern the medical conditions PANS (Paediatric Acute-Onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections).

In particular, the objects are:

- 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).
- To relieve the need of sufferers (and families) of the medical conditions PANS and PANDAS by the provision of support, education, and practical advice.



PANS PANDAS UK have been a great support to us over the last 9 months, and I admire all of the incredible strides forward you are making.

6.2 The Main Activities Undertaken

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

6.2.1 Policy Development

During 2024/25 some significant milestones were met towards improved healthcare for people with PANS and PANDAS in the UK.

6.2.1.1 All Party Parliamentary Group

The PANS PANDAS All Party Parliamentary Group (APPG) was relaunched following the change in Government with 32 members including 4 officers.

6.2.1.2 NHS Scotland

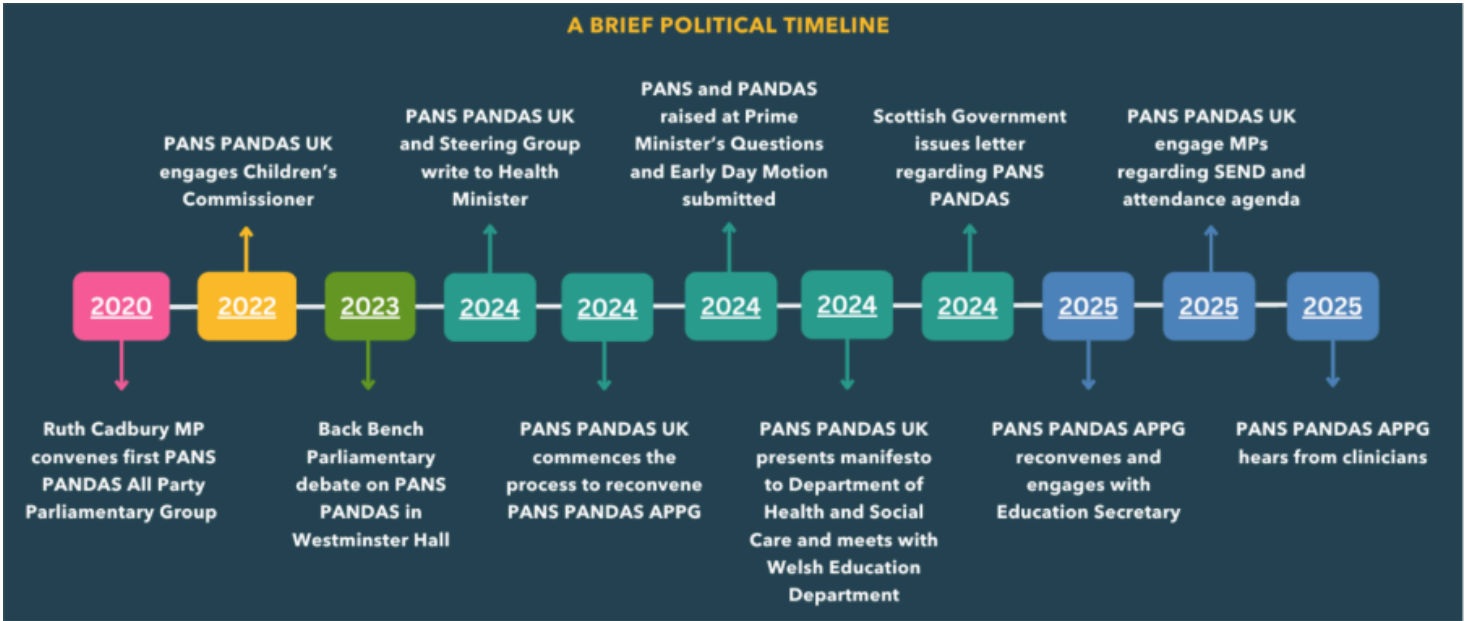
NHS Scotland wrote to outline their support for patients with PANS and PANDAS.

6.2.1.3 Education Briefing Document

PANS PANDAS UK responded to the Children’s Wellbeing and Schools Bill and wrote an Education Briefing Document.

6.2.1.4 Manifesto for Change

PANS PANDAS UK and the PANS PANDAS Steering Group (PPSG) wrote to the Secretary of State for Health and Social Care, Wes Streeting MP. Baroness Merron responded, inviting PANS PANDAS UK, Chair of the APPG Wendy Chamberlain MP and a clinician to meet with her in parliament. We presented a manifesto outlining what needs to change and how that fits within the NHS 10 Year plan.



6.2.2 PANS PANDAS Steering Group

For more information about the PANS PANDAS Steering Group please visit www.theppsg.org.uk

6.2.2.1 Clinical Guidelines Working Group

This year, the PANS Clinical Guideline Development Group was established with support from RCPCH. Two independent co-chairs were appointed, terms of reference established, the scope drafted, consulted on and finalised. A literature review was undertaken (completion due Summer 2025) and work began to identify candidates to participate in the Delphi study.

6.2.2.2 Education, Social Care and Health Working Group

On 23 May 2024, the Education, Social Care, and Health Group (ESCHG) convened its inaugural online meeting. This multidisciplinary group brings together 18 professionals from educational psychology, psychotherapy, social care leadership, teaching, SEND and Inclusion, and commissioning. It is co-chaired by a Designated Clinical Officer and the Education Lead from PANS PANDAS UK.

PANS and PANDAS are complex conditions requiring coordinated, multi-agency responses. To address disparities in awareness and support across Local Authorities, The ESCHG is developing a position statement. This will clarify the roles and responsibilities of professionals in health, education, and social care when supporting children and young people with suspected or diagnosed PANS/PANDAS. The statement will also highlight training needs and outline current care and education pathways. The ESCHG has completed a first draft.

6.2.2.3 Research Working Group

The PANS PANDAS Research Working Group was formed to expedite high quality UK research into these conditions. One of the key initiatives of the PANS PANDAS Research Working Group has been to submit applications to the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance Service (CAPSS) to better understand the incidence of PANS and PANDAS in the UK. We await results from the stage 1 application but expect the response to be positive. Subsequent research will centre around early phase treatment and will map out service development including acute presentations, the refractory group of patients and the relapsing group of patients. The intention is that this should lead into early intervention and antibiotic studies.

6.2.3 Rebranded and launched new website

We were delighted to launch our new branding and new website in May 2024 which we hope represents our mission more clearly. Our new website is easier to navigate and contains an accessibility widget to enable as many people as possible to access our resources and information more easily.

6.2.4 Awareness Day 'ask the experts' campaign with Youth Board

During Awareness Day our amazing Youth Board asked international expert clinicians some of the questions for which they have been seeking answers. Recordings of the clinicians answering those questions were used as part of our Awareness Day campaign and are now live on our website here: [Ask the Experts](#)

6.2.5 Collaboration with Taming Olivia - Youth Board

Our amazing Youth Board has been working closely with OCD support organisation, Taming Olivia, on an exciting creative project to share information about PANS and PANDAS with young people. The Youth Board have co-created a character called Glitch, to represent the conditions and development of a comic strip is underway.



6.2.6 Launched our Friends of PANS PANDAS UK scheme

We launched our Friends of PANS PANDAS UK (FOPP) scheme which is so much more than a regular giving scheme. FOPP will help create a sense of belonging and togetherness, enabling us to use our collective voice, but also providing us with a better understanding of the number of people who we are supporting.

6.2.7 Development of two Community Reference Groups

To ensure that the voices of our communities are at the heart of our work, we established two Community Reference Groups in May 2024, one for England and Wales, and one for Scotland and Northern Ireland. These groups were created to provide a structured and meaningful way for us to listen to, learn from, and collaborate with the people and communities we serve.

6.2.8 Appointment of a CEO

Interviews for a Chief Executive Officer were undertaken and the former Chair of Trustees, Vicky Burford was appointed as CEO, with a start date of June 2025.

6.2.9 Community Survey

A survey of our community to understand better the ways in which they would like us to be communicating with them was undertaken in January 2025. The results of this survey will be shared with our community and used to develop a communications strategy during the next financial year.

6.2.10 CPD Accredited Teacher Training

Due to the popularity of our CPD Accredited Teacher Training, we increased the number of sessions we are delivering and recruited 2 new trainers and one new support assistant. During the 2024/25 financial year we delivered 38 training sessions attended by a total of 1,163 educational professionals.



Thank you for helping us, we will be forever grateful.

6.2.11 Annual Community Fundraising Campaign

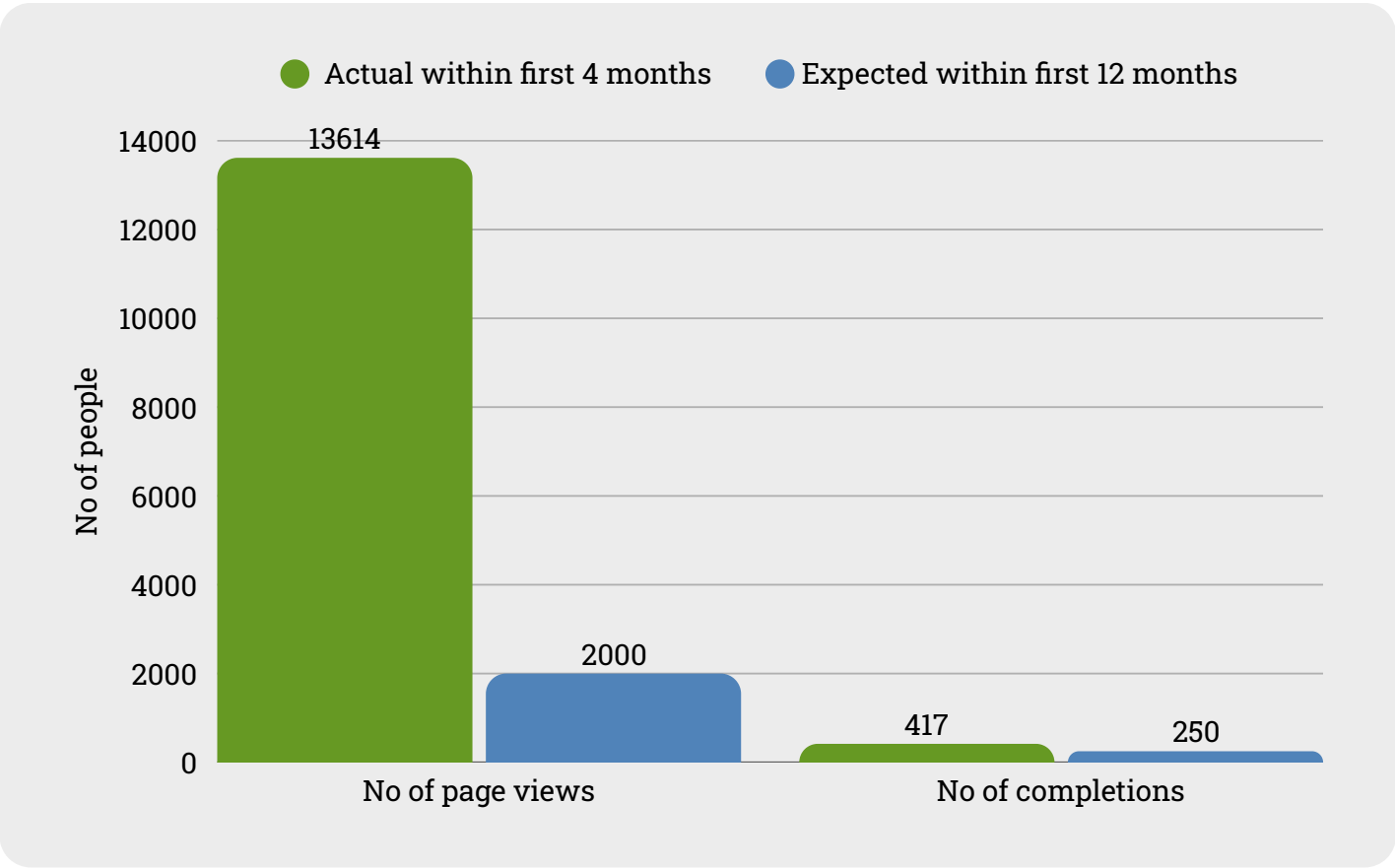
In July 2024 our second ‘Choose your Challenge’ campaign took place during the month of July. Living with PANS and PANDAS is a challenge every day, and so we ask people during the month of July to get out of their comfort zones and challenge themselves to do something difficult and raise money for PPUK at the same time. Our incredible community got behind us and raised over £30,000 during the course of this campaign.

6.2.12 CPD Accredited Learning Module for Doctors

We worked closely with MIMS Learning to create a CPD accredited e-learning module for UK healthcare professionals in primary and secondary care.

This short module is the first of its kind and aims to improve awareness of childhood acute neuropsychiatric conditions, describing what PANDAS is and how to diagnose it and what the current recommendations are for treatment. Since launching the PANDAS-specific module in October 2024, MIMS Learning has reported hundreds more completions than they would usually anticipate in a module of this kind. This demonstrates healthcare professionals’ growing interest in learning more about acute neuropsychiatric conditions.

This table demonstrates the number of anticipated views and completions expected within the first 12 months of the module launch (blue) and the actual number of views and completions within only the first 4 months (green).



6.2.13 Health and Education Conference Attendance

We attended a variety of health and education related conferences during the 2024/25 financial year including:

- The Royal College of GPs conference in October 2024, where we exhibited and spoke to many interested GPs about the conditions and noticed a significant increase in the number of GPs aware of the conditions.
- The Royal College of Paediatrics conference in March 2025, where we were honoured to be selected for a highly competitive workshop slot. The session, titled "Perspectives on PANS and PANDAS", was well attended and delivered in collaboration with three distinguished paediatric specialists, offering a range of expert insights.
- The NASEN Live Education Conference in July 2024 where we engaged with a wide range of education professionals, raising awareness of the educational impacts of PANS and PANDAS, and sharing our resources including the offer of free training.
- The TES SEND Education Conference in September 2024, which provided a valuable opportunity to connect with SEND leaders and practitioners. We shared insights into the challenges faced by children with PANS and PANDAS in educational settings and promoted our resources and guidance for schools.

6.2.14 Council for Disabled Children

We delivered a presentation to the Council for Disabled Children in September 2024 highlighting the need for greater recognition of PANS and PANDAS within disability and inclusion frameworks. The session sparked valuable connections with other organisations and charities, inspired new initiatives such as our manifesto, and provided an opportunity to share updates on the health and education system streams currently underway.



I could not have survived to this point without the incredible wealth of knowledge offered by the charity.

Section 7: Achievements and Performance

We report on our performance and achievements on several measures.

7.1 Our Main Mission

At PANS PANDAS UK, our purpose is to serve the community affected by PANS and PANDAS. We understand that this community is made up of individuals and families with a wide range of shared experiences, and we are committed to listening and responding to their diverse needs. We try to ensure that everything we do is guided by ongoing engagement with the community, helping to shape our direction and ensure our work remains relevant and impactful.

Our mission is to improve the health and wellbeing of everyone affected by these conditions across the UK.

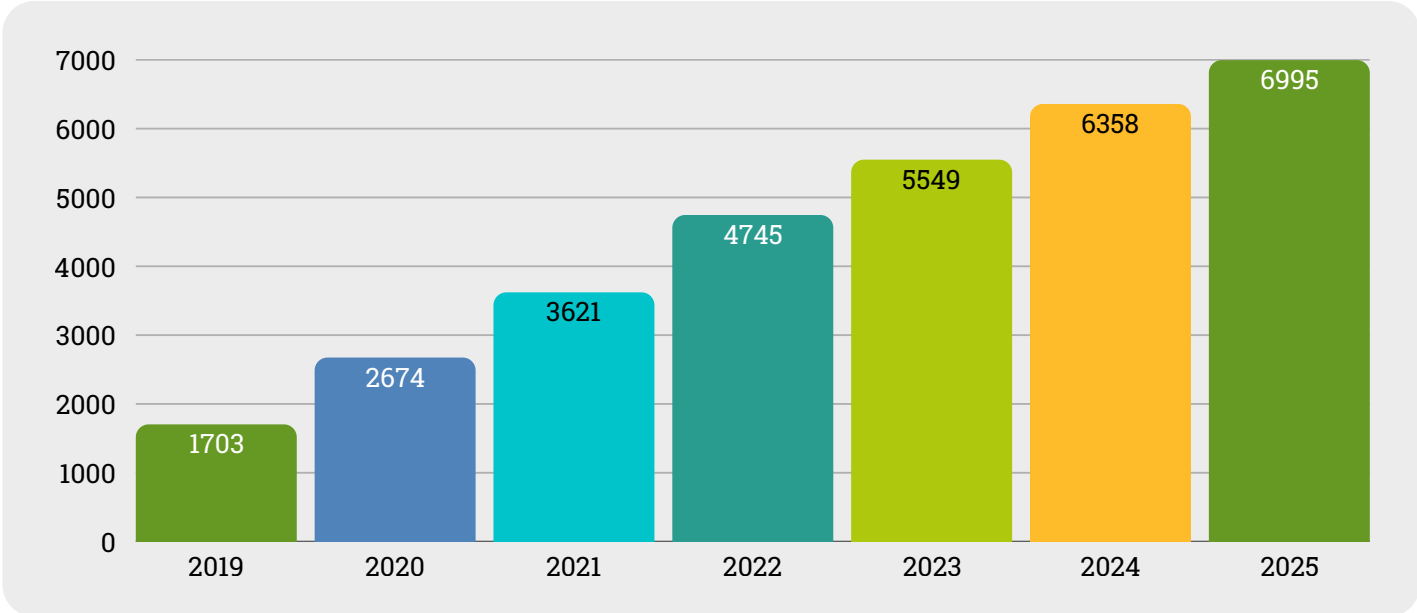
We work closely with healthcare and education professionals to build knowledge and understanding, so that individuals presenting with symptoms potentially linked to PANS or PANDAS receive appropriate assessment, and those diagnosed have equitable access to care, diagnosis, and treatment, no matter where they live or how much money they have.

We are also committed to providing clear, accessible information and resources to support families and individuals. This includes guidance on diagnosis, healthcare pathways, symptom management, and educational support.

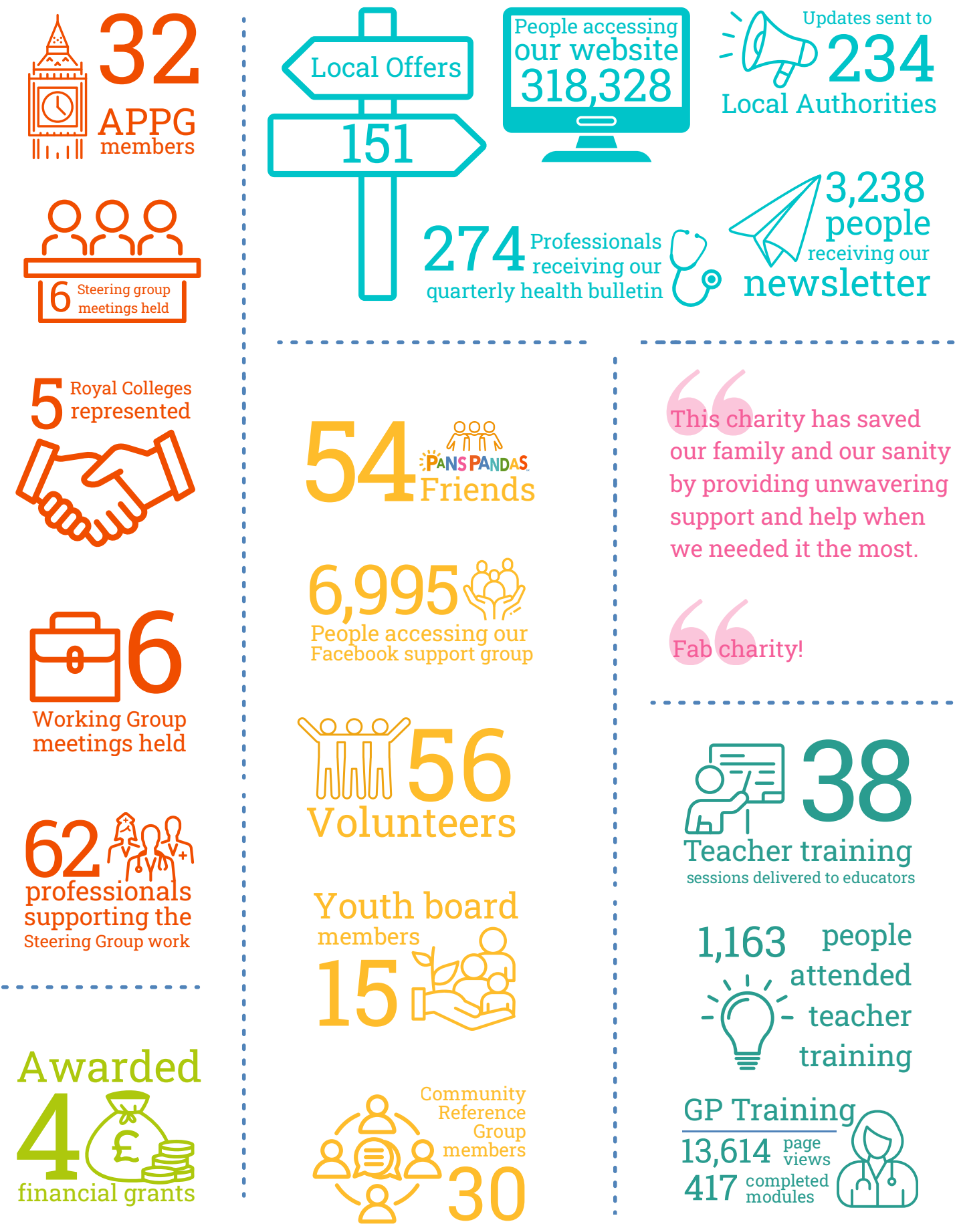
Above all, we are striving for lasting, systemic change, so that everyone affected by PANS or PANDAS receives the excellent, effective, and equitable care they deserve.

7.2 “Members”

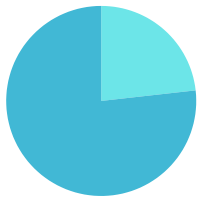
We did not have a formal membership scheme in place during the last financial year and so we have used our Facebook support group as our measure. We continue to see a steady growth in numbers joining our Facebook support group year on year.



7.3 Our Impact at a glance

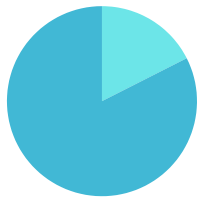
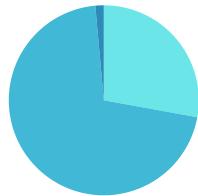


Teacher Training Impact



100% agreed or strongly agreed that presentation materials were relevant and clear

98.5% agreed or strongly agreed that pace and content was appropriate for audience



100% agreed or strongly agreed that the programme content would raise awareness of PANS and PANDAS

100% would recommend our teacher training to colleagues



Teacher Training Feedback

“The slides were great, and the trainer was very knowledgeable. It was helpful that it covered all areas of PANS/PANDAS including presentations in school and things we should be mindful of.”

“Knowledgeable and passionate host”

“Incredibly informative - detailed and breadth of information”

“Clear and easy to understand information with very helpful tips on PANS PANDAS in the school setting and highlighting the unique challenges in a way that is easy to understand.”



Follows up by
59%

Visits up by
40%

Facebook reach up
58%



Content Interactions up
100%

Visits up by
1.5%

Instagram reach up
114%



Reactions
1,935

Reposts
130

LinkedIn Impressions
57,332



Due to new charges by the social media platform X, we are unable to access our analytics, however we believe that our twitter presence has grown in line with the activity on our other social media platforms.

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 2024 to 31 March 2025 (a minor adjustment of the reporting year-end to align with our monthly reporting software).

We use a financial software package called Xero to manage and monitor our financial transactions, as it is a piece of software compatible with HMRC requirements, and familiar to our Examiner.

Our financial results have been independently examined and the examiner reported that there were no issues of any concern.

This Annual Report contains three relevant appendices:

- Appendix A is the Charity Commission Form CC16a;
- Appendix B is the Independent Examiner's Report;
- Appendix C is the Statement of Financial Activities, containing:
 - The Profit and Loss Account;
 - The Balance Sheet;
 - The Notes to the Accounts.

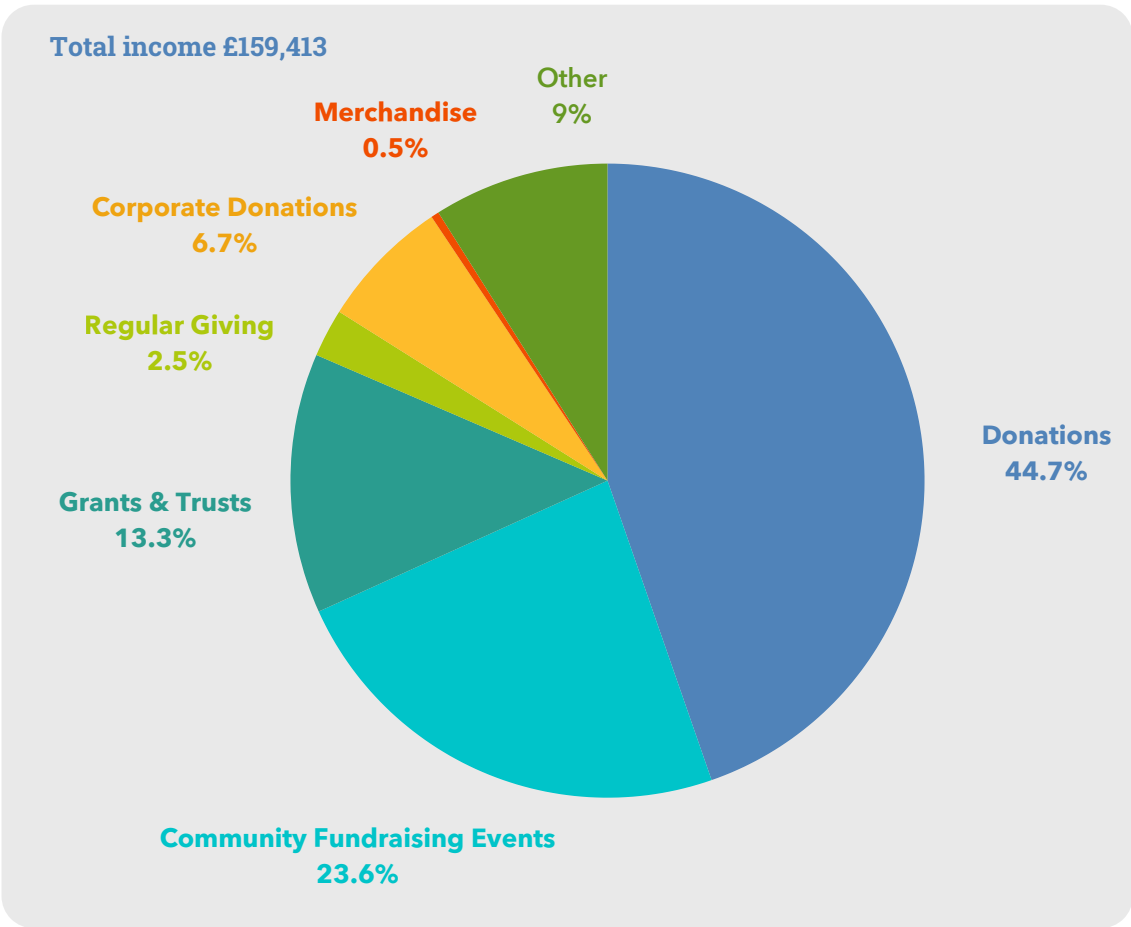
To follow is a brief summary of those statutory documents.



PANS PANDAS UK are a lifeline of information and support. We would be completely lost and alone without them.

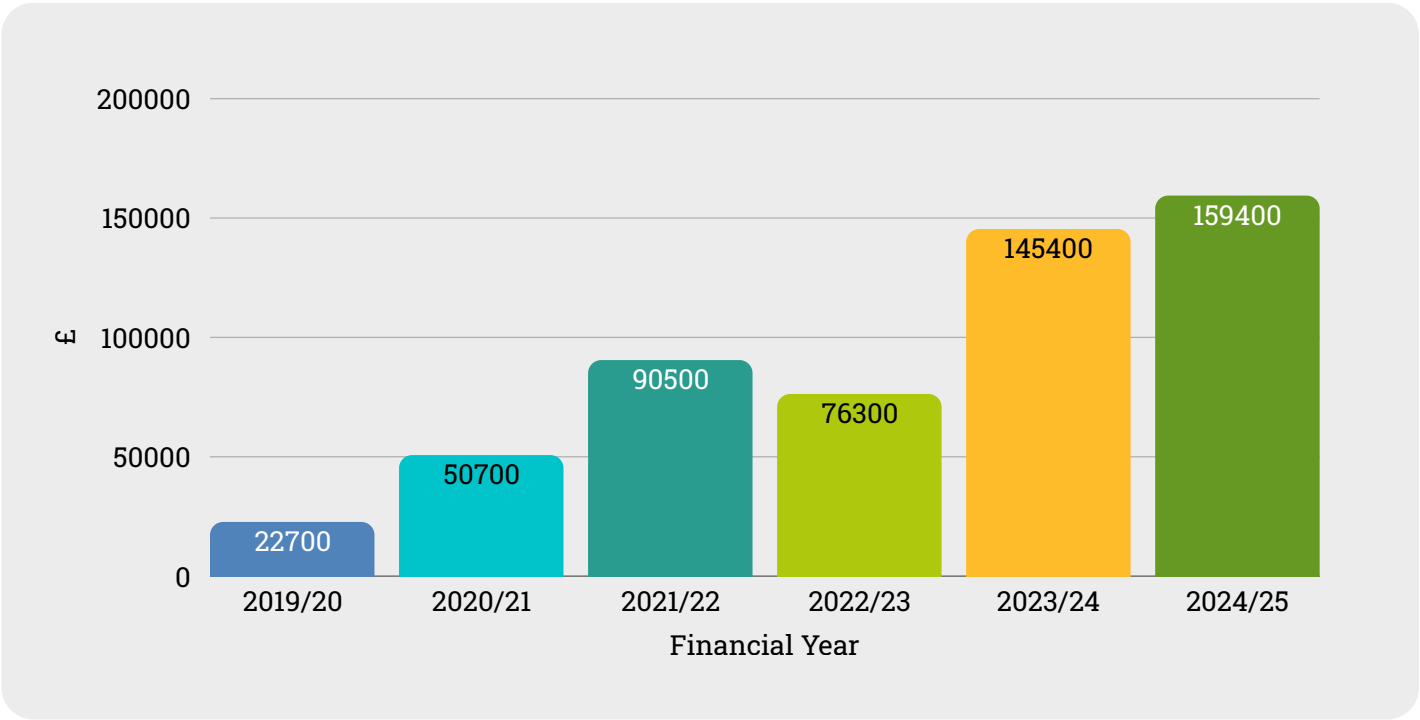
8.2 Income in 2024-25

The chart below presents the sources of income during the financial year, together with the percentage represented by each source.



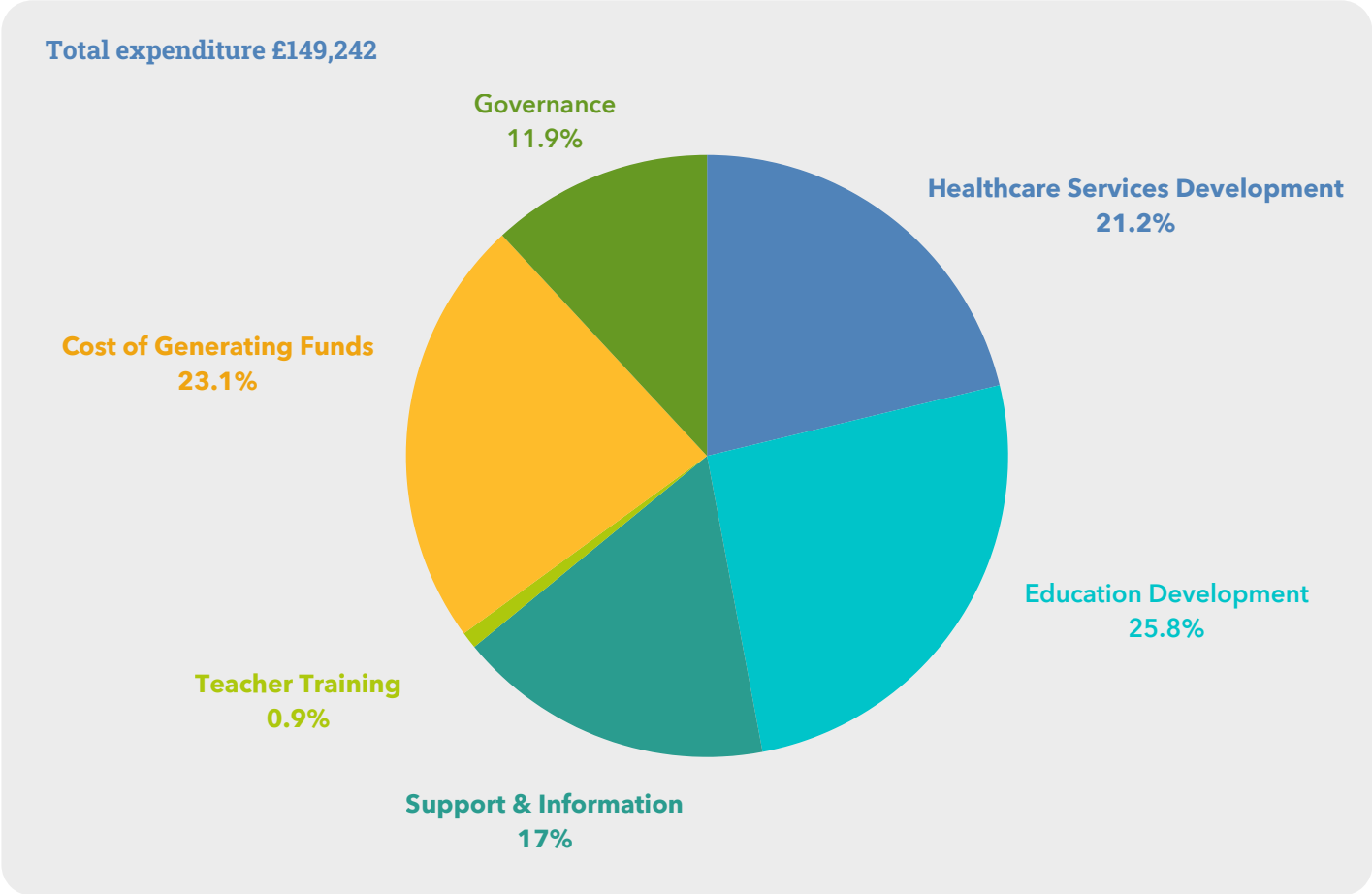
8.3 Historic Income Trends

The graph below shows the historic income trends.



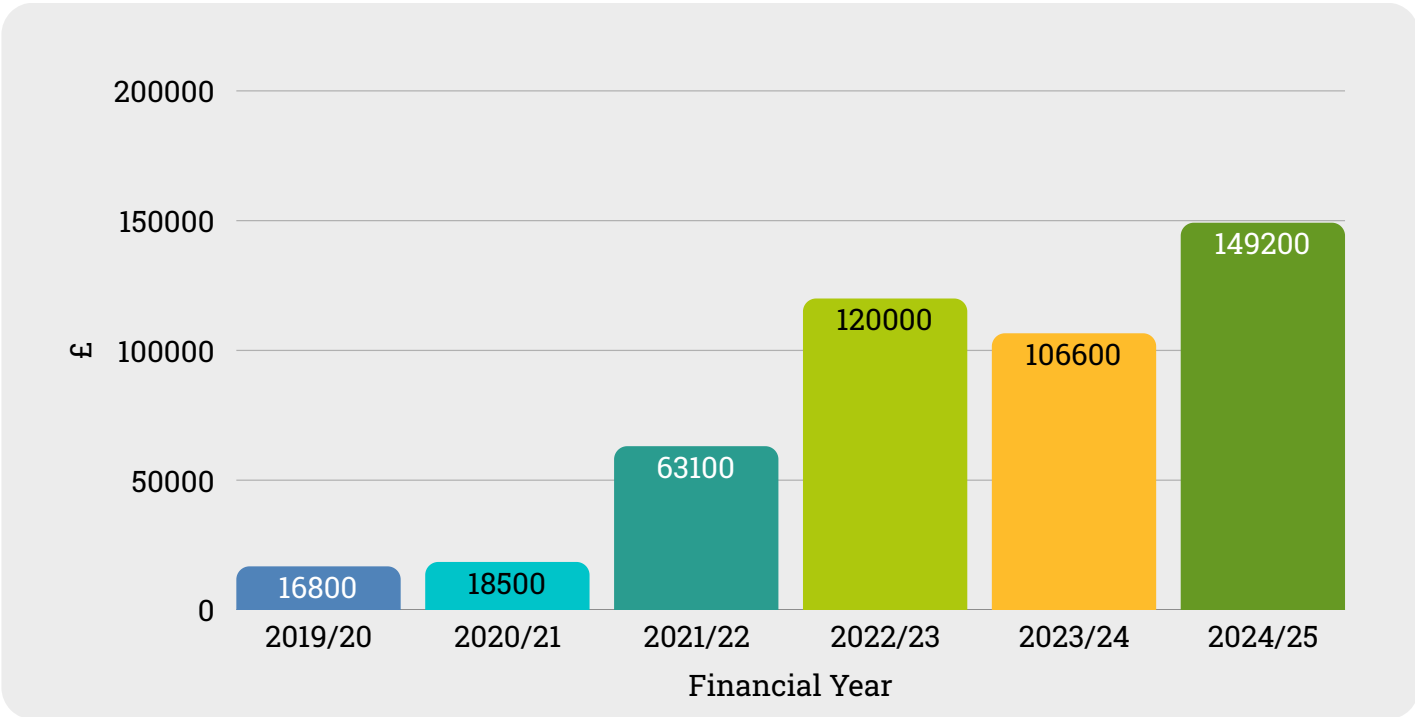
8.4 Expenditure in 2024-25

The chart below presents the sources of expenditure during the financial year, together with the percentage represented by each source.



8.5 Historic Expenditure Trends

The graph below shows the historic expenditure trends.



8.6 Reserves

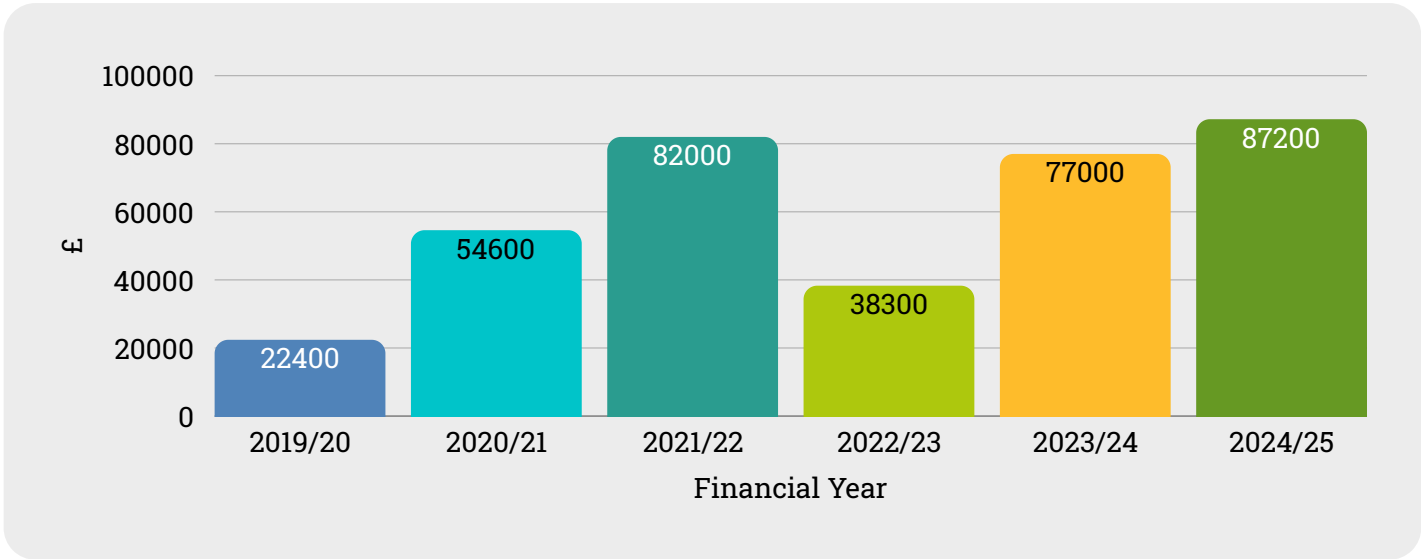
The appropriate level of reserves was based on a risk-based approach for both restricted and unrestricted funds. This approach, which considered a number of plausible threats to income and expenditure, resulted in a figure representing about 6 months’ turnover, which is consistent with advice from the Charity Commission for a charity of this size.

The table below presents the reserves position at the start and the end of the financial year.

Table 8.1 Reserves	
Total Reserves Held as at 31 st March 2025	£87,208
Of which, held in Restricted Funds	£65,354
Of which, held in Unrestricted Funds	£21,854
Total Reserves as a Proportion of Annual Turnover	55% (6.5 months of turnover)

The level of unrestricted reserves represents only 14% of our annual turnover, less than 2 months. The level of reserves will be kept under review in 2025-26.

The chart below presents the reserves held at the end of each financial year.



8.5 Funds in deficit

The charity has no 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

11.1 Financial Year 2025/26

Although only larger charities subject to statutory audit are required to provide details of plans for future periods, we nevertheless provide headlines for planned activity in the financial year 2025/26.

11.1.1 Building Momentum for Change

As we look to the year ahead, PANS PANDAS UK is entering an exciting phase of growth, collaboration, and impact. Our plans span across the UK and touch every area of our work; from clinical progress and research to community engagement and professional education.

11.1.2 All Party Parliamentary Group

We're excited about the next phase of our work with the All-Party Parliamentary Group (APPG) on PANS and PANDAS, and we have some ambitious plans in motion.

To begin with, we're preparing to host a special session in early summer, where clinical experts will be invited to meet with APPG members. This will be a valuable opportunity to deepen understanding of PANS and PANDAS among parliamentarians, ensuring they are well-informed and equipped to advocate for meaningful change.

Following this, we're planning a drop-in event at Parliament. There will be an open invitation for MPs to hear directly from members of our community. These personal stories and lived experiences are powerful, and we believe they will help bring the realities of PANS and PANDAS to the forefront of political discussion.

Looking further ahead, we're working towards a second Backbench Debate, this time with a dedicated focus on the challenges around access to healthcare experienced by our community. This will be another important moment to raise awareness, push for progress, and ensure that the voices of those affected by PANS and PANDAS are heard at the highest levels.

11.1.3 PANS PANDAS Steering Group (PPSG)

To increase visibility and accessibility, we'll be launching a dedicated website for the PPSG. This platform will showcase the group's work and serve as a central hub for related documents and updates.

11.1.4 Engaging NHS Trusts

We'll be reaching out to all NHS Trust Chief Executives across the UK with an update on the PPSG's work, encouraging them to share this information with their GP and paediatric teams to raise awareness and improve clinical understanding.

11.1.5 Clinical Guidelines Working Group

The literature review that will inform the Delphi process is nearing completion. Once finalised, the Delphi process will begin. This is an essential step in developing robust, evidence-based clinical guidelines.

11.1.6 Pathway/Service Specification Group

As the Delphi process concludes, we'll begin shaping a clear referral pathway and service specification. This will help clinicians navigate diagnosis and treatment once the guidelines are published.

11.1.7 Education, Social Care and Health Working Group

The first draft of our guidance is complete and now undergoing internal review. We will then be identifying key external stakeholders to provide feedback, before the guidance is published ensuring the guidance is comprehensive and practical.

11.1.8 Research Working Group

Our applications for the Child and Adolescent Psychiatric Surveillance System (CAPSS) and British Paediatric Surveillance Unit (BPSU) surveillance studies are progressing to the second phase. If successful, they will move forward to ethics approval, marking a major milestone in NHS-led research into PANS and PANDAS.

11.1.9 Virtual Conference for Parents and Carers

We're excited to host a week-long virtual conference filled with expert-led webinars and workshops designed to support and empower parents and carers. We will bring together experts from education, psychotherapy, occupational therapy, speech and language therapy, social work, benefits support, and so much more to provide our community with practical and useful information and support.

11.1.10 Educational Psychologist Training

We will expand our teacher training provision by developing a CPD accredited training module for Educational Psychologists, with a view to launching this training in September 2025.

11.1.11 Youth Advisory Board

Our Youth Board continues to lead with creativity and passion. The Taming Olivia comic strip collaboration is set to launch soon, and we're planning to expand this work with new resources and merchandise. We're also hopeful that National Lottery Community Fund support will allow us to recruit a dedicated Youth Worker to help deliver a youth-led project.

11.1.12 Building Organisational Resilience

To secure the future of our work, we're investing in our organisational resilience, strengthening our foundations so we can continue to grow and support our community for years to come.

11.1.13 Communications Strategy

We are developing a new communications strategy following feedback received from our community via a survey launched in the last financial year, to ensure we're engaging with our community in meaningful, accessible, and responsive ways.

11.1.14 Supporting the Devolved Nations

We hope to secure funding to launch a scoping exercise to better understand the specific needs of our community members in Scotland, Wales, and Northern Ireland. This will help us tailor our support and advocacy efforts, ensuring that no one is left behind, regardless of where they live.

11.1.15 Conferences, Webinars and Workshops

We'll be attending a range of health and education conferences to raise awareness and share knowledge with professionals. Highlights include:

- A hybrid workshop at the Birmingham School of Dentistry's training day in June 2025, focusing on the impact of dental treatment on patients with PANS and PANDAS.
- Attendance at the Royal College of General Practitioners Annual Conference in Wales this autumn as exhibitors, continuing our efforts to engage with primary care professionals.

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 2024 to 31st March 2025.

Signed: 

Name: Vicky Burford

Position: CEO, Former Chair of Trustees, PANS PANDAS UK

Date: 31 October 2025

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

Section 13: Appendices

Appendix A

Independent Examiner's Report

Appendix B

Statement of Financial Activities, containing:

- The Profit and Loss Account;
- The Balance Sheet;
- The Notes to the Accounts.

**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 the Charity for the period ended 31st March 2025.

Responsibilities and basis of report

As the charity Trustees of the company (and also its directors for the purposes of company law) you are responsible for the preparation of the accounts in accordance with the requirements of the Companies Act 2006 ('the 2006 Act').

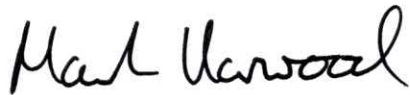
Having satisfied myself that the accounts of the company are not required to be audited under Part 16 of the 2006 Act and are eligible for independent examination, I report in respect of my examination of your company's accounts as carried out under section 145 of the Charities Act 2011 ('the 2011 Act'). In carrying out my examination I have followed the Directions given by the Charity Commission under section 145(5)(b) of the 2011 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 company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

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.



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

Date: 12th November 2025

PANS/PANDAS UK

STATEMENT OF FINANCIAL ACTIVITIES
for the Period 6th April 2024 – 31st March 2025

6th April 2024 – 31st March 2025					Year Ended 5 th April 2024			
Notes	Unrestricted £	Restricted £	Total £	Unrestricted £	Restricted £	Total £		
Income from:								
Donations & legacies	2	79,270	77,354	156,624	144,134	-	144,134	
Other trading activities		647	-	647	406	-	406	
Other		2,142	-	2,142	815	-	815	
Total income		82,059	77,354	159,413	145,355	-	145,355	
Expenditure on:								
Charitable activities:								
Health services development	3	29,766	2,000	31,766	22,328	-	22,328	
Education development		28,526	10,000	38,526	24,765	-	24,765	
Patient information and support		25,430	-	25,430	14,295	-	14,295	
Youth Advisory Board		-	-	-	880	-	880	
Research		-	-	-	4,368	632	5,000	
Teacher Training		1,301	-	1,301	-	-	-	
Total charitable activities		97,023	12,000	97,023	66,636	632	67,268	
Raising funds	4	34,439	-	34,439	28,128	-	28,128	
Governance	5	17,780	-	17,780	11,191	-	11,191	
Total expenditure		137,242	12,000	149,242	105,955	632	106,587	
Net income/(expenditure)		(55,183)	65,354	10,171	39,400	(632)	38,768	
Transfers between funds		-	-	-	24,669	(24,669)	-	
Net movement in funds		10	(55,183)	65,354	10,171	(25,301)	38,768	
Fund balances brought forward			77,037	-	77,037	12,968	25,301	38,269
Fund balances carried forward			21,854	65,354	87,208	77,037	-	77,037

PANS/PANDAS UK

BALANCE SHEET
As at 31st March 2025

	Note	31/03/2025 Unrestricted £	31/03/2025 Restricted £	31/03/2025 Total £	05/04/2024 Unrestricted £	05/04/2024 Restricted £	05/04/2024 Total £
Current assets							
Debtors	8	1,010	-	1,010	-	-	-
Cash at bank and in hand		23,489	65,354	88,843	77,122	-	77,122
Total current assets		24,499	65,354	89,853	77,122	-	77,122
Current liabilities							
Creditors	9	(2,645)	-	(2,645)	(85)	-	(85)
Net current assets		21,854	65,354	87,208	77,037	-	77,037
Total assets less current liabilities	10	21,854	65,354	87,208	77,037	-	77,037

The financial statements were approved by the Trustees on 24th October 2025.

On behalf of the Trustees



Mr Andrew Koss
Chair

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Period 6th April 2024 – 31st March 2025

1. ACCOUNTING POLICIES

a) Basis of preparing the financial statements

PANS/PANDAS UK is a Charitable Incorporated Organisation registered in England & Wales and Scotland. The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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 issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011, Charities Accounts (Scotland) Regulations 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention and are presented in sterling which is the functional currency of the charity and rounded to the nearest £1.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

b) Income

All incoming resources are included in the Statement of Financial Activities (SoFA) when the charity is legally entitled to the income after any performance conditions have been met, the amount can be measured reliably and it is probable that the income will be received.

For donations to be recognised the charity will have been notified of the amounts and the settlement date in writing. If there are conditions attached to the donation and this requires a level of performance before entitlement can be obtained then income is deferred until those conditions are fully met or the fulfilment of those conditions is within the control of the charity and it is probable that they will be fulfilled.

Donations, grants and gifts given for specific purposes are treated as income in the year of receipt. Unspent restricted income is included under restricted funds as it is fully committed.

No amounts are included in the financial statements for services donated by volunteers. Further detail is given in the Trustees' Annual Report.

Income from trading activities includes activities to raise funds for the charity. Income is received in exchange for supplying goods and services in order to raise funds and is recognised when entitlement has occurred.

c) Expenditure

Expenditure is included on an accruals basis, and has been classified under headings that aggregate all cost related to the category. Expenditure is recognised where there is a legal or constructive obligation to make payments to third parties, it is probable that the settlement will be required and the amount of the obligation can be measured reliably. Where costs cannot be directly attributed, they have been allocated on a basis consistent with the use of resources (see 1.d) below).

Irrecoverable VAT is charged as an expense against the activity for which expenditure arose.

Redundancy and termination costs are recognised as an expense in the SoFA and a liability on the Balance Sheet immediately at the point the charity is demonstrably committed to either: terminate the employment of an employee or group of employees before normal retirement date; or provide termination benefits as a result of an offer made in order to encourage voluntary redundancy. The charity is considered to be demonstrably committed only when it has a detailed formal plan for the termination and is without realistic possibility of withdrawal from the plan.

d) Allocation of expenditure

Salaries - The salaries of project workers are allocated directly to the projects on which they work, alongside the charity's contribution to pensions where appropriate.

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Period 6th April 2024 – 31st March 2025

1. ACCOUNTING POLICIES - continued

d) Allocation of expenditure - continued

Other costs - Core costs are allocated to the expenditure headings in the Statement of Financial Activities as follows:

	Administration Costs %	Communications Costs %
Health services development	30	20
Education development	30	20
Patient information and support	30	20
Youth Advisory Board	0	0
Research	0	0
Cost of generating funds	5	40
Governance	5	0
	100	100

	Administration Costs £	Communications Costs £
Health services development	10,665	1,617
Education development	10,665	1,617
Patient information and support	10,665	1,618
Youth Advisory Board	-	-
Research	-	-
Cost of generating funds	1,778	3,235
Governance	1,777	-
	35,550	8,087

e) Taxation

The charity is an exempt charity within the meaning of schedule 3 of the Charities Act 2011 and is considered to pass the tests set out in Paragraph 1 Schedule 6 Finance Act 2010 and therefore it meets the definition of a charitable company for UK corporation tax purposes.

f) 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.

g) Debtors and creditors receivable / payable within one year

Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure.

h) Pension costs and other post-retirement benefits

The charity operates a defined contribution pension scheme. Contributions are expensed as they become payable.

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Period 6th April 2024 – 31st March 2025

2. DONATIONS AND LEGACIES INCOME

	6th April 2024 – 31st March 2025			Year Ended 5 th April 2024		
	Unrestricted £	Restricted £	Total £	Unrestricted £	Restricted £	Total £
Regular giving	3,913	-	3,913	3,163	-	3,163
Major donors	-	60,354	60,354	15,307	-	15,307
Individuals	10,863	-	10,863	23,316	-	23,316
Companies/Organisations	10,677	-	10,677	21,494	-	21,494
Trusts & foundations	4,133	17,000	21,133	-	-	-
PPUK fundraising events	22,244	-	22,244	6,386	-	6,386
Community-led events	15,304	-	15,304	57,862	-	57,862
Gift Aid	12,136	-	12,136	16,606	-	16,606
Total donations and legacies	79,270	77,354	156,624	144,134	-	144,134

3. CHARITABLE ACTIVITIES EXPENDITURE

	6th April 2024 – 31st March 2025			Year Ended 5 th April 2024		
	Unrestricted £	Restricted £	Total £	Unrestricted £	Restricted £	Total £
Project costs	20,316	-	20,316	12,790	632	13,422
Project staff costs	27,860	12,000	39,860	34,726	-	34,726
Administration*	31,995	-	31,995	15,965	-	15,965
Communications*	4,852	-	4,852	3,155	-	3,155
Total expenditure on charitable activities	85,023	12,000	97,023	66,636	632	67,268

* = see Note 1.c)

4. COSTS OF GENERATING FUNDS

	6th April 2024 – 31st March 2025			Year Ended 5 th April 2024		
	Unrestricted £	Restricted £	Total £	Unrestricted £	Restricted £	Total £
Merchandise	527	-	527	48	-	48
Resources & materials	1,345	-	1,345	1,279	-	1,279
Event costs	494	-	494	7,699	-	7,699
Platform fees	2,456	-	2,456	3,063	-	3,063
Professional fees	14,815	-	14,815	12,360	-	12,360
Other fundraising costs	656	-	656	20	-	20
Staff costs	9,133	-	9,133	669	-	669
Administration*	1,778	-	1,778	887	-	887
Communications*	3,235	-	3,235	2,103	-	2,103
Total expenditure on raising funds	34,439	-	34,439	28,128	-	28,128

* = see Note 1.c)

PANS/PANDAS UK

NOTES TO THE ACCOUNTS
for the Period 6th April 2024 – 31st March 2025

5. GOVERNANCE COSTS

	6th April 2024 – 31st March 2025			Year Ended 5 th April 2024		
	Unrestricted	Restricted	Total	Unrestricted	Restricted	Total
	£	£	£	£	£	£
Trustee expenses/costs	3,081	-	3,081	1,604	-	1,604
Insurance	974	-	974	832	-	832
Accountancy software	442	-	442	384	-	384
Bookkeeping	7,200	-	7,200	4,212	-	4,212
Independent examiner	2,340	-	2,340	2,040	-	2,040
HR services	1,951	-	1,951	1,232	-	1,232
Other costs	15	-	15	-	-	-
Administration*	1,777	-	1,777	887	-	887
Total governance costs	17,780	-	17,780	11,191	-	11,191

* = see Note 1.c)

6. STAFF COSTS

	6th April 2024 – 31st March 2025 £	Year Ended 5 th April 2024 £
Gross wages	66,484	45,764
Pension costs	1,922	1,270
Other employee costs	3,425	-
Total salaries, wages and related costs	71,831	47,034
Average number of employees	6	4

No employee earned £60,000 per annum or more.

Total redundancy/termination payments amount to £3,425 (2024 - £nil) and related to the Administration Manager position which was deemed to be no longer required following a restructure.

7. TRUSTEES' REMUNERATION AND EXPENSES

No Trustee or connected person received any remuneration or expenses either directly or indirectly.

8. DEBTORS

	31.03.25 £	05.04.24 £
Prepayments	1,010	-
	<u>1,010</u>	<u>-</u>

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Period 6th April 2024 – 31st March 2025

9. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	31.03.25 £	05.04.24 £
Trade creditors	264	-
Other creditors	941	85
Accruals	1,440	-
	<u>2,645</u>	<u>85</u>

10. MOVEMENT IN FUNDS

	Funds at 06.04.24 £	Incoming resources £	Expended resources £	Transfers £	Funds at 31.03.25 £
Unrestricted (General) fund	77,037	82,059	(137,242)	-	21,854
Restricted funds:					
Hospital Saturday Fund	-	2,000	(2,000)	-	-
Education Fund	-	10,000	(10,000)	-	-
Information & Support Fund	-	5,000	-	-	5,000
The BIG Give	-	20,354	-	-	20,354
Caudwell Fund	-	40,000	-	-	40,000
	<u>-</u>	<u>77,354</u>	<u>(12,000)</u>	<u>-</u>	<u>65,354</u>
TOTAL FUNDS	<u>77,037</u>	<u>159,413</u>	<u>(149,242)</u>	<u>-</u>	<u>87,208</u>

11. RESTRICTED FUNDS

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

Hospital Saturday Fund

Grant funding received from The Hospital Saturday Fund for the development of UK Clinical Guidelines for PANS and PANDAS.

Education Fund

Grant funding received from the James Tudor Foundation for the delivery of teacher training.

Information & Support Fund

Grant funding received from the Quilter Foundation for the development of information resources about PANS and PANDAS, specifically for the community of children and young people affected.

The BIG Give

Christmas Campaign income towards delivery of an online community conference in 2025 and an in-person international conference in 2026.

Caudwell Fund

Donation received from Rebekah Caudwell towards the costs of the CEO salary and Health Services Development work.

12. RELATED PARTY DISCLOSURES

There were no related party transactions during the year.

Accounts



Year ending 5 April 2024

PANS PANDAS UK

Annual Report 2023/24



Introduction

I am pleased to present this Annual Report for 2023-24 which describes what the charity has achieved over the last year, and how our income has been used to further our objectives. To say this has been an eventful year would be an understatement, and it is quite remarkable how much has been achieved when one considers how small the team is.

We are a small team, but a mighty one, and before I talk about any of the progress which has been made, I must pay tribute to everyone who has played a part in it. I must thank the Trustees for their tireless commitment to ensuring that PANS PANDAS UK (PPUK) is well governed. I applaud the staff team, who astound me time after time with their dedication to doing an incredible job, and their determination to make things better for everyone affected by PANS and PANDAS. It is a privilege to work alongside them.

Then there are our superb volunteers and the invaluable contributions they make to the work of the charity. I want to acknowledge every single person who has undertaken a fundraising challenge, donated or shared a post on social media, written to their MP or taken a leaflet to their GP. All awareness raised and income received is because of the efforts of our supporters and we are so very grateful to them. We are conscious of the additional challenges faced by our community due to the cost-of-living crisis and are grateful to them for their continued support.

I am particularly proud of our Youth Board members who met with the Deputy Leader of the Scottish Liberal Democrat party, Wendy Chamberlain MP last year to talk about the impact of living with PANS and PANDAS.



Their contributions became the focus of the Parliamentary Debate in Westminster Hall in September 2023 which was facilitated by the PANS PANDAS All Party Parliamentary Group. The debate was well attended by MPs from across the political parties and all four UK nations. It was heartening to see that there was true cross-party consensus about the importance of improving care for PANS and PANDAS, and to hear the Health Minister, Maria Caulfield acknowledge that 'we have the evidence to sufficiently demonstrate that PANS and PANDAS are discrete disease entities.' and then later to speak about the conditions during a television interview. I am confident that without the Youth Board's input to this debate, we would not have made such progress in our health and education work.

Finally, I want to express my admiration for the incredibly brave and inspiring PANS PANDAS Community throughout the UK. The support and encouragement we receive from our community despite their ongoing challenges powers us on. That they came together in such numbers to vote for our awareness video at the Smiley Charity Film Awards this year was something quite special. Winning the people's choice award has really helped us to raise the profile of these conditions to a much broader audience. Thank you to everyone who voted.

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

[Section 4:](#) Reference and Administrative Details

[Section 5:](#) Structure, Governance and Management

[Section 6:](#) Objectives and Activities

[Section 7:](#) Achievements and Performance

[Section 8:](#) Financial Review

[Section 9:](#) Funds Held as Custodian Trustee on Behalf of Others

[Section 10:](#) Public Benefit Statement

[Section 11:](#) Plans for Future Periods

[Section 12:](#) Signed Statement

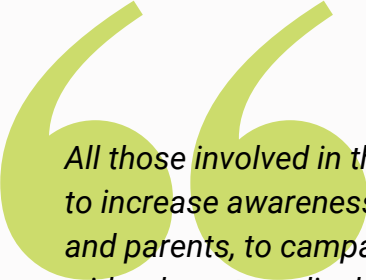
Section 1: What are PANS and PANDAS, and what is PANS PANDAS UK?

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 (PPUK) operates nationally across the UK and was granted charity status in England and Wales on 22 May 2018 and then in Scotland on 20 March 2024. PPUK has 5 part time employees (2.5 FTE) and utilises the experience of two independent contractors.

Please visit our website for more information:

www.panspandasuk.org



All those involved in the charity PANS PANDAS UK have worked tirelessly to increase awareness of PANS and PANDAS, to educate professionals and parents, to campaign and petition the government, to lobby and work with relevant medical royal colleges, so as to establish correct treatment pathways and improve care and support for children and young adults who are suffering from these terrible life-altering yet under-recognised and under-diagnosed neuropsychiatric conditions.

For so many families struggling to cope with what often suddenly presents as a myriad of new symptoms and behaviours - along with the disbelief or parental blame that is sadly so commonplace from medics, mental health counsellors, educational professionals and social workers - the PANS PANDAS UK charity is a beacon of hope and an amazing source of information, advice and support.

Section 2: This Annual Report - General

This Annual Report for the financial year 2023-24 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

PANS PANDAS UK is registered with the Charity Commission for England and Wales: 1178484 and the OCSR in Scotland: SC053206

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, who can be contacted at vicky.burford@panspandasuk.org or via the Charity's registered office below.

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 (resigned 15/6/23)

Trustee: Diane Palmer

Trustee, Company Secretary: resigned (1/2/24)

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

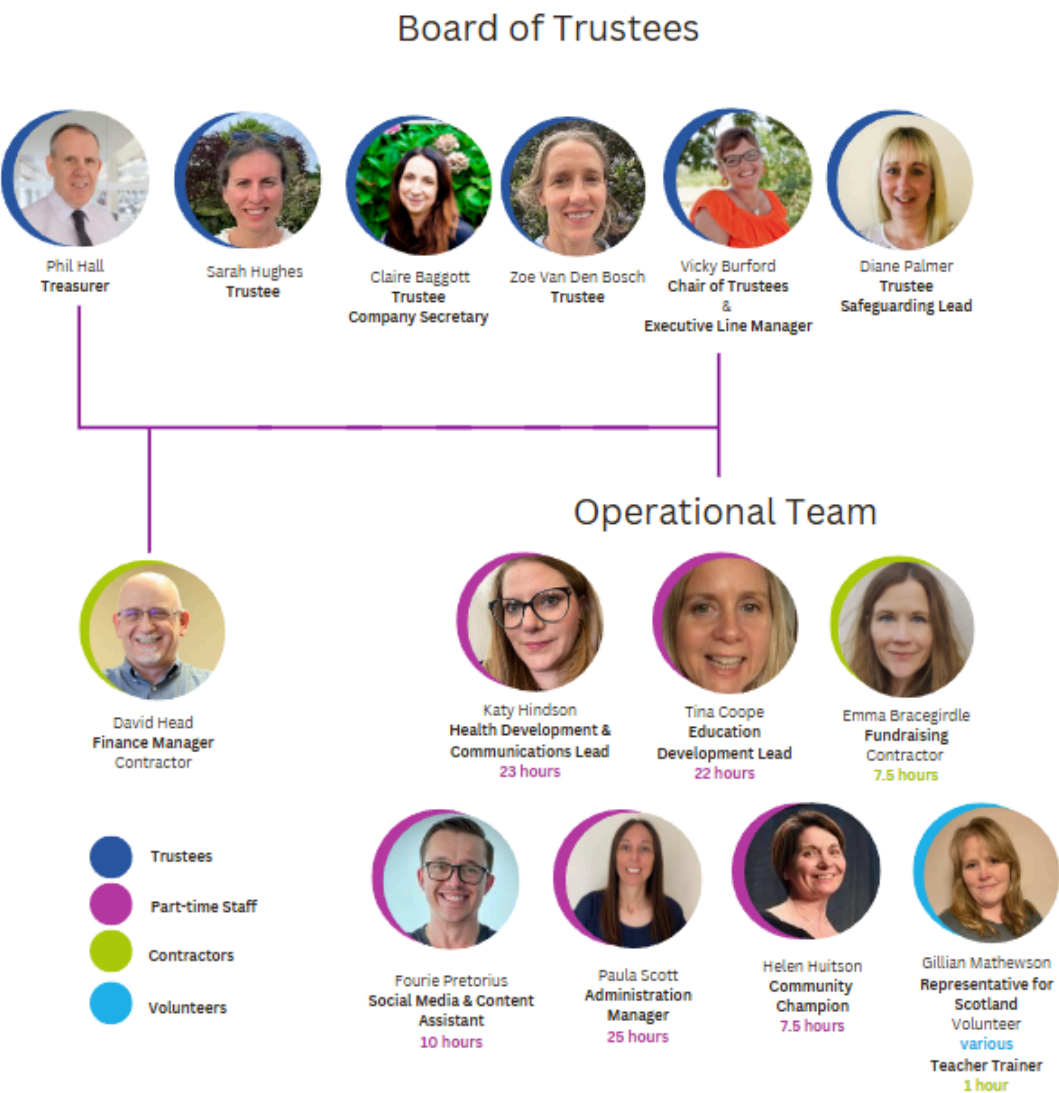
Section 5: Structure, Governance and Management

5.1 The Governing Document

PPUK has a formal Constitution, which was approved by the Charity Commission on 22 May 2018. A review of our Constitution was made by the Trustees in early 2024 with a view to simplifying the document and clarifying our charitable objectives. This revision is still being reviewed by the Charities Commission at the time of publishing this report.

5.2 Our Organisation Chart

The governance and operational structure of PPUK for the year ending 5th April 2024 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 Operational Team

The work of the charity is carried out by our operational team. The charity currently has 5 employed staff all working on a part time basis.

Alongside the employed staff, the charity is supported by 3 contracted staff members, Finance Manager, Fundraising Lead and Teacher Trainer.

The total part time hours worked are equivalent to 2.8 full time employees.

The work of the team is also supported by some excellent and committed volunteers.

The operational team report to the Chair of the Board who currently line manages the team.

5.5 Corporate Governance Standards

In this reporting year, PPUK continued developing its corporate governance framework following the board approved plan set out during 2022/23 to ensure that we follow industry-specific best practice standards.

As part of this PPUK is strongly committed to further enhancing its risk management framework, with work actively being undertaken to mitigate risk and help the charity continue to grow and become more resilient.

5.6 Risk Management

Following the implementation of a robust risk management framework for the charity during the previous reporting year, work on a risk identification and assessment process for greater clarity on the charity's risk profile continues. Further developments will be implemented during 2024/2025 to ensure that effective risk management remains fully integrated into the charity's strategic and operational activities.

Section 6: Objectives and Activities

6.1 The Purposes of the Charity

The charity's purposes concern the medical conditions PANS (Paediatric Acute-Onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections).

In particular, the objects are:

- The provision of practical support, information and advice to the sufferers (and families) of PANS and PANDAS;
- To advance the education of the general public in all areas relating to PANS and PANDAS;
- To advance the education and improve understanding amongst health, social work and education professionals in all areas relating to PANS and PANDAS.
- To accelerate and support UK led research into PANS and PANDAS and their impact on the people affected by them.



Simply put, this charity has saved our lives. My 6 year old daughter suffered with symptoms from the age of 2. Lack of awareness meant nobody could help her because all the ASD strategies, Occupation Therapy and Ed Psych involvement in the world can't treat brain inflammation.

When we found the charity's website and the Facebook support group it truly was a lifeline for our daughter and our family. Their GP leaflet and advice from the support group helped us get a referral to Neurology despite the GP never having heard of it before.

6.2 The Main Activities Undertaken

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

6.2.1 Healthcare Development Progress

2023 was a year which saw some very promising steps towards improved healthcare for people with PANS and PANDAS in the UK.

History

The PANS PANDAS Steering Group (PPSG) was formed in late 2022 with the support of NHS England. This group published a statement in 2023 which recognised that access to healthcare across the UK for these conditions was uneven and recommended that NHS trusts should develop multidisciplinary teams to improve the service for these patients.

During the financial year 2023/24 we built upon this foundation by establishing four sub-groups:

- The Research Group
- The Consensus Guidelines Development Group
- The Service Specification Group
- The Education, Social Care and Health Group

Research Group

More research into PANS and PANDAS will play an important part in making sure that the NHS is able to provide improved services with accurate diagnosis and treatment. The first activity of this group has been to submit an application for a UK-wide surveillance study which will give an indication of the number of people presenting with symptoms of PANS and PANDAS. This information will play a critical role in encouraging research into the conditions and allowing the NHS to understand better the need for improved services. Following on from this, the Research Group will look to establish UK-led trials into which treatments are most effective in treating PANS and PANDAS.

Consensus Guidelines Development Group

Working in parallel with the Research Group is the Clinical Guideline Development Group. The purpose of this group is to reach agreement on a UK guideline for the treatment of PANS and PANDAS, based upon what is currently known about the conditions

These guidelines are Royal College guidelines rather than NICE guidelines (for which the results of the surveillance study and further UK research are necessary). The Guideline Development Group recognises that, whilst work progresses towards the point where NICE guidelines are appropriate, there is a clear need for better provision in the meantime.

This group began work in Spring 2024 and gathered professionals from the fields of Neurology, Psychiatry, Immunology, Infectious Diseases, General Practice, Nursing, Clinical Psychology and Paediatrics from across the UK nations. Attendees from both paediatric and adult health services attended and consideration was given to paediatric care and also to transitions and how to improve care for an adult cohort of patients. PANS PANDAS UK and parent representatives were in attendance, as were patient representatives.

[Service Specification Group](#)

This sub-group will follow on directly from the guidelines work. This group will look at creating practical pathways and services for PANS and PANDAS which are able to deliver the principles laid out in the guidelines. Work on this group has not yet started and only appears here for information and to enable a fuller understanding of the work of the PPSG.

[Education, Social Care and Health Group](#)

This group aims to create a usable guide for professionals, children, young people and their families which will improve support available across education, health and social care. Preliminary work on this group has started but the first meeting is not due to take place until June 2024. This information appears here only for information and to enable a fuller understanding of the work of the PPSG.

We know that none of this can happen quickly enough for all those currently living with PANS and PANDAS. Historically, access to appropriate healthcare and support has been incredibly limited and the situation remains very challenging across the UK. We are doing our utmost to drive the work of these groups forward and to work collaboratively with the government, the Royal Colleges, NHS England and the National Institute for Health Research to ensure that prompt and appropriate support is available across the UK for everyone living with these conditions within as short a time as possible.

6.2.2 Westminster Hall Debate in Parliament

The 12th of September 2023 was a landmark day for all those living with PANS and PANDAS in the UK. A backbench debate, secured by Deputy Leader of the Scottish Liberal Democrats and member of the All Party Parliamentary Group for PANS and PANDAS, Wendy Chamberlain MP, was held in Westminster Hall to discuss the conditions and to ask the Parliamentary Under-Secretary of State for Health and Social Care, Maria Caulfield MP, to respond to the issues raised by the other MPs in attendance.

The debate was very well attended by MPs from across the political parties and from all four UK nations. That was in no small part due to the incredible effort from PANS and PANDAS community members to call for their respective MPs to speak on their behalf at the debate. 16 MPs were present, and several more who were unable to attend asked those present to speak for them. In the public gallery, representatives from PANS PANDAS UK and interested clinicians were also in attendance.

The debate saw MPs recount the stories of their constituents, and highlight the current barriers to appropriate, informed and timely healthcare for young people affected by PANS and PANDAS. Wendy Chamberlain spoke movingly of the experiences shared when she met with members of the PANS PANDAS UK Youth Advisory Board. Speakers called upon Maria Caulfield to respond as to how the government intends to improve support and provision for all those with the conditions.

It was heartening to see that there was true cross-party consensus about the importance of improving care for PANS and PANDAS, and to hear Maria Caulfield acknowledge that 'we have the evidence to sufficiently demonstrate that PANS and PANDAS are discrete disease entities.' We are even more delighted to hear her commitment to ensuring that those with the conditions get the care they need and to work in collaboration with the PANS PANDAS All Party Parliamentary Group and PANS PANDAS Steering Group to move forwards in developing the evidence base through high quality research.

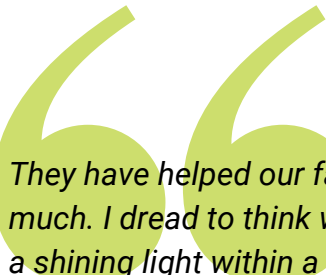
6.2.3 Safeguarding and Fabricated and Induced Illness (FII) guide for professionals

During FII Week in May 2023 our Safeguarding and FII guide for professionals was published.

We know that many UK families with children who have PANS and PANDAS are currently subject to safeguarding referrals or allegations of Fabricated or Induced Illness. The factors behind why this is happening are multiple and complex, but the impact on families is simple. Families who are already struggling to support a medically complex child are being further traumatised by being blamed for their child's illness.

In collaboration with Cathleen Long (independent social worker and co-author of the recent British Association of Social Work's practice guidance on FII and Perplexing Presentations), PANS PANDAS UK has written a guide for social work, healthcare and education professionals. You can read it in full [here](#).

The guide sets out the reasons why so many PANS and PANDAS families are unfairly being accused of harming their child. It explores what professionals can do differently to ensure that all children are kept safe without unnecessarily targeting families of children with medical conditions. It makes recommendations about how professionals can work collaboratively and, in a trauma-informed way to assess any children presenting with symptoms of these post-infectious disorders. We encourage all relevant professionals to take the time to read this guide.



They have helped our family and so many other families so much. I dread to think where we would be without them. They are a shining light within a very dark place for many families across the UK promoting awareness of an unknown and misunderstood condition that has devastating affects despite being easy treat if identified early enough

6.2.4 Presented at the British Paediatric Neurology Association Annual Conference in January 2024

PANS PANDAS UK chairperson, Vicky Burford took to the stage in the main auditorium alongside a number of eminent doctors as part of a research workshop for PANS and PANDAS.

This research workshop on PANS and PANDAS was chosen as one of only four workshops delivered throughout the three-day conference. In front of an audience of well over 150 paediatric neurologists from across the UK, the speakers gave an overview of the conditions, the work currently underway with the PANS PANDAS Steering Group, and what UK research trials for treatment of PANS and PANDAS might take place in future.

Vicky Burford spoke of the growing numbers of children, young people and adults living with PANS and PANDAS, the huge challenges they face and the damage done by the 2021 publication of the BPNA Consensus Statement on PANS and PANDAS. This was followed by a progress report on the PANS PANDAS surveillance study application, and details on the formation of the consensus guidelines development group and the education working group. The workshop was incredibly well received.

"I was delighted to see such interest in PANS and PANDAS and the work being carried out to end the current variation in care. For me, today really showed how much progress has been made in the past few years. Whilst change cannot happen quickly enough for our community, it is clear now that professionals are increasingly aware of the conditions and are willing to contribute meaningfully towards improved standards of care."

Vicky Burford, Chair of Trustees

Most amazing charity in the world. Many children and parents wouldn't know where to go without PANS PANDAS UK. This charity is not just supporting families, but also informing teachers and doctors. Thank you PANS PANDAS UK for everything you do!

6.2.5 Attended the Royal College of Paediatrics and Child Health (RCPCH) Annual Conference as an Exhibitor

In March 2024, with the help of our fantastic volunteers, we spoke to hundreds of paediatricians, medical students and other health professionals about PANS and PANDAS. It was brilliant to hear that increasing numbers of doctors are aware of the conditions, and to see true professional curiosity and engagement from those who had yet to hear about them.

6.2.6 Recruited a volunteer to lead on the work in Scotland

Gillian Mathewson is a Principal Teacher of Maths in Aberdeenshire in Scotland. Gillian joined the PANS PANDAS UK Education team in September 2023, delivering the online teacher training to teachers across the UK, and since then has started to gather information around the educational support available for children in Scotland with the conditions. Her current focus is on identifying the mechanisms in place to support children who are unable to attend school due to their PANS or PANDAS, as this is an area that is distinctly different from the other UK Nations.

Prior to becoming a teacher Gillian was an Engineer, working in programme management and software development, so has a wide range of skills at her disposal to help drive forward the message in Scotland.

6.2.7 Became registered as a charity in Scotland

With an official presence in Scotland, we were able to apply for charitable status in Scotland. Charity status was granted by the Scottish Charity Regulator on 20th March 2024. This significant milestone enables us to engage with public bodies across Scotland, amplifying our efforts to raise awareness and advocate for change on behalf of everyone affected by PANS and PANDAS throughout Scotland. this new chapter allows us to extend our reach and support networks, building upon the impactful work already underway throughout the rest of the UK.

6.2.8 Roll out of in-person family meetings around the UK

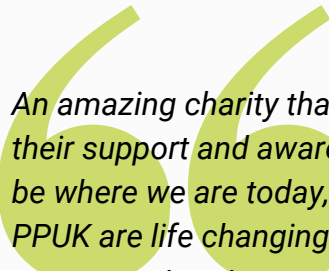
Our community told us that they wish they could get together in person with other families, and our Youth Board reported wishing they could meet other children with PANS or PANDAS in person. We listened and recruited a part time Community Champion to develop a plan to develop and roll out the in-person family meetings blueprint across the UK.

6.2.9 Fortnightly Zoom meetings

We held a volunteer-led Zoom meeting every two weeks 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.

6.2.10 Teacher Training – CPD accredited

Our CPD Accredited Teacher Training webinars have proven to be very popular amongst educators and we expanded our reach with the development of dedicated training courses for a wider audience including educational psychologists, Special Education Needs and Disabilities (SEND) professionals, Designated Clinical Officers, who are professionals who sit between health and education for local boards, and Universities. During the 2023/24 financial year we delivered 18 teacher training sessions attended by a total of 939 educational professionals. The first University teacher training session was also delivered to Weston University and the training has also been requested by and delivered to specialist SENCO networks, Local Authorities, in conjunction with Twinkl and the Autism teaching company amongst others.



An amazing charity that literally saved our boy's life, without their support and awareness raising I am certain we would not be where we are today, a happy, healthy boy back at school. PPUK are life changing! They consistently go over and above, across sectors to secure the health and wellbeing of our children. Who otherwise would not have a voice or treatment or access to their education, some would even not survive. They have truly been magnificent!

6.2.11 PANS and PANDAS on the University Curriculum for educators

PANS and PANDAS education resources have been shared and delivered to both undergraduate and post graduate education students at Gloucester University, Sunderland University, Birmingham Newman University and Manchester Metropolitan University (MMU) Additionally the MMU are currently in the process of developing an undergraduate SEND degree and will be collaborating with the charity to include PANS and PANDAS on the curriculum. Earlier this year Birmingham Newman University also collaborated with the charity and are now delivering an integrated PANS and PANDAS module in their teaching degrees. Some of these Universities are now educationally networking about PANS and PANDAS independent of the charity and we look forward to seeing the outcomes.

6.2.12 Development of Resources

In the last financial year, we developed a variety of information resources, some of which have been mentioned specifically in this report. Others include the leaflet for Paediatricians and GPs a presentation for parliamentarians called 'What people living with PANS and PANDAS want you to know'. We also began work on a leaflet for CAMHS professionals.

In addition, extensive new resources have been published over the last year via a variety of external education networks and platforms:

- SEND network
- EdpsychEd website
- SEND resources blog
- Twinkl
- An independent PANS and PANDAS dyslexia blog
- NASEN Connect (A national SEND magazine)

Work with education professionals also led to the inclusion of PANDAS in Sarah Johnson's 'All about SEMH book' and her resource on Emotionally Based School Avoidance (EBSA).

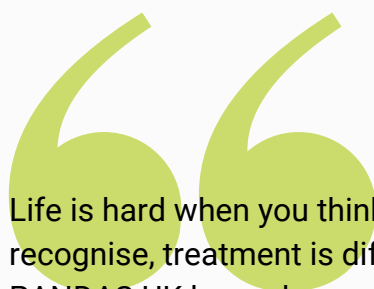
6.2.13 Launched an Annual Fundraising Campaign

In July 2023 PPUK launched a 'Choose your Challenge' campaign, our biggest fundraising campaign yet. Living with PANS and PANDAS is a challenge every day, and so we asked people during the month of July to get out of their comfort zones and challenge themselves to do something difficult and raise money for PPUK at the same time. Our incredible community got behind us and raised over **£50,000** during the course of this campaign.

6.2.14 Exhibited at a variety of education conferences

The PANS PANDAS UK team was delighted to have the opportunity to attend the National SEND (Special Educational Needs and Disabilities) and Inclusion Conference 2024 in Leicester, exhibiting alongside Miranda Barker, Senior Lecturer in Education and SEND at Birmingham Newman University.

It was a fantastic environment for networking with multiple opportunities to spread the word further and raise the profile of PANS and PANDAS amongst leaders within the education profession. It was heartening to hear that many professionals had already heard of the conditions and were fully committed to providing appropriate support and spreading further awareness amongst colleagues. The charity has also attended the Family Voice Norfolk conference and the Schools and Academies show. Both conferences led to multiple networking opportunities with ICB SEND commissioners, SEND leads, the Department for Education, National Association of Head Teachers and OFSTED amongst others.



Life is hard when you think you're alone dealing with an illness few recognise, treatment is difficult to find and there's no support. PANS PANDAS UK have shown us that we are not alone.

Since joining them we have learnt more about the condition and have made some great friends along the way who understand exactly what we are going through.

6.2.15 PANS and PANDAS on the Teacher Training Curriculum at Birmingham Newman University

Birmingham Newman University have now included PANS and PANDAS across their initial teacher training courses, reaching more than 200 students every academic year.

They are also going the extra mile to raise awareness amongst all of their SEND partners. We are so grateful to Birmingham Newman University, and in particular lecturers Miranda Barker and Andrew Edgar in the Faculty of Education for their support and enthusiasm for raising the profile of PANS and PANDAS.

6.2.16 Delivered educational workshops at the National Award for Special Educational Needs Coordination Conference (NASENCO)

As a result of an education presentation on PANS and PANDAS at the University College in London, the charity was invited to present at the annual NASENCo (National Association for Special Educational Co-ordinators) conference at Manchester Metropolitan University. Following the conference the PANS and PANDAS education resources were shared across the relevant university faculties, PANS and PANDAS were included on the NASENCo training course and the resources and information shared across wider local and national SENCO networks.

6.2.17 Numerous Collaborations with various educational institutions/educators

Whilst the medical world of PANS and PANDAS continues to advance, shaping guidelines, identifying incidence figures, and developing clinical pathways, children and young people with these conditions are currently sitting in classrooms with their symptoms underestimated and/or misinterpreted with (in many cases) devastating consequences.

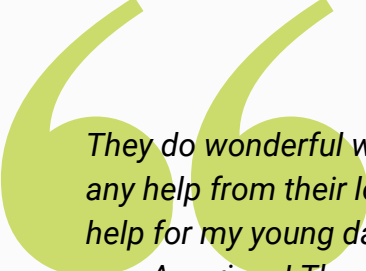
PANS PANDAS UK has worked collaboratively with multiple educational institutions such as:

- Twinkl
- Teach First
- Inspiration Trust
- Family Voice
- EPNET (educational psychology forum)
- EdpsychEd (independent educational psychology training website)
- the SEND Network, and NASEN (National Association of Special Educational Needs).

This is alongside work with high profile individuals in education including:

- Sarah Johnson (president of PRUSAP (Pupil Referral Units and Alternative Provision))
- Louise Selby (specialist support teacher for dyslexia)
- Georgina Durrant (SEN Resources blog)
- Discover Inclusion
- Cath Kitchen (Chair of the National Association for Hospital Education (NAHE) and
- Michelle Racey (Designated Clinical Officer)

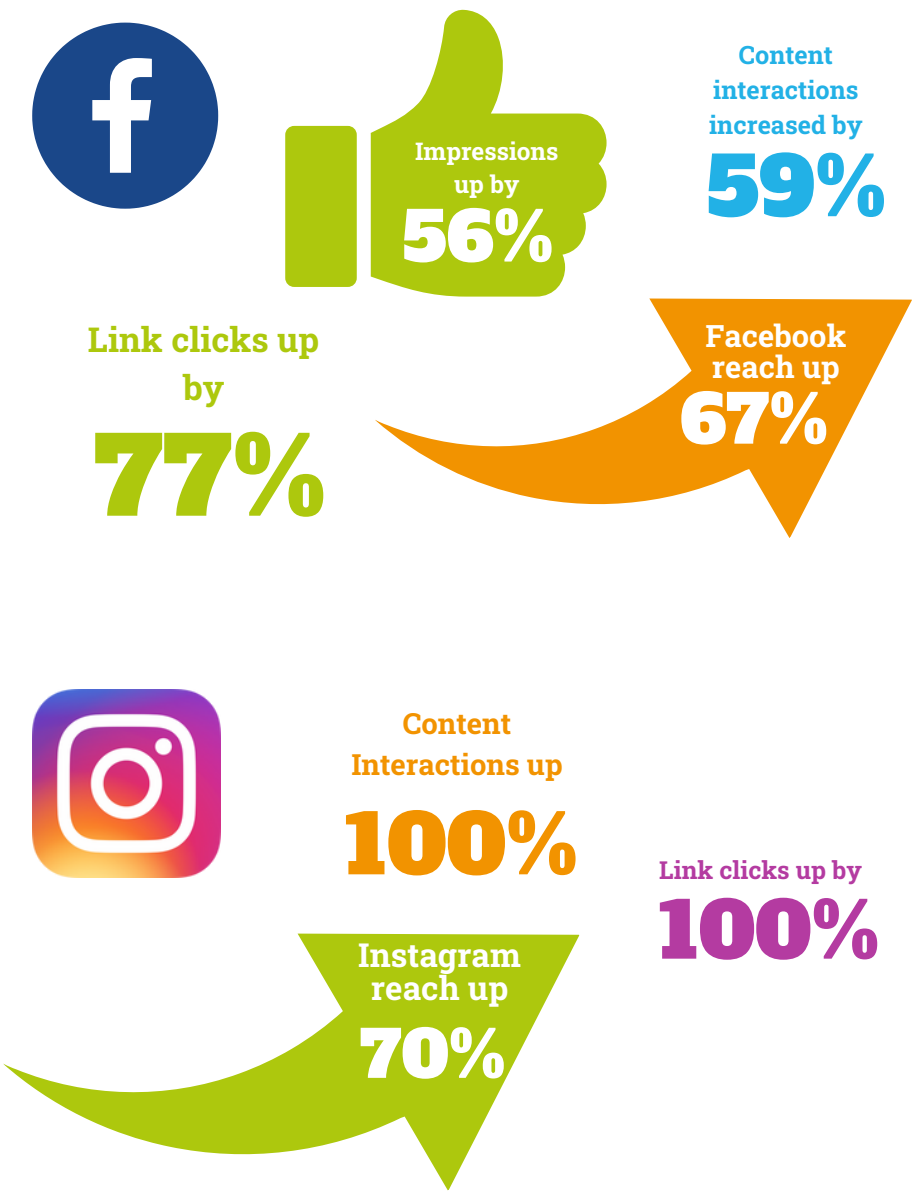
These collaborative strands of work have led to multiple new PANS and PANDAS education resources being published, raised awareness across different sectors of education, provided opportunities to deliver the teacher training over a larger network, the inclusion of PANS and PANDAS in education projects such as the 'Voices of Dyslexia' and the opportunity to join wider networks such as the Health Conditions in Schools Alliance, the Parent Carer Forum Networks, the Council for Disabled Children and the Special Educational Consortium.



They do wonderful work helping families who cannot get any help from their local NHS services - we were refused help for my young daughter because the GP said the illness was American! The charity have been a lifeline when we had nowhere else to turn

6.2.18 Social Media Presence

We increased our social media presence during 2023/24



Due to new charges by the social media platform X, we are unable to access our analytics, however we believe that our twitter presence has grown in line with the activity on our other social media platforms.

Section 7: Achievements and Performance

We report on our performance and achievements on several measures.

7.1 Our Main Mission

We exist to serve the community affected by PANS or PANDAS. We recognise that it is made up of various groups based on common experiences. Everything we do is based on assessment of our community’s wants and needs which in turn supports our direction and purpose.

It is our 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.

We will provide information and resources to help inform and support families and individuals about diagnosis of PANS and PANDAS, healthcare, managing symptoms and educational support.

We build relationships with healthcare and education professionals to increase understanding, empathy and support of those affected by PANS and PANDAS.

We strive for systemic change to ensure excellent, effective and equitable treatment for everyone affected by PANS or PANDAS

7.2 “Members”

We did not have a formal membership scheme in place during the last financial year and so we have used our Facebook support group as our measure. We continue to see a steady growth in numbers joining our Facebook support group year on year.



7.3 Service User Feedback

Here are some of the comments we have received from our community members during the course of the last financial year. You will see further comments elsewhere in this report.

PANS PANDAS UK are a wonderful charity with a wealth of information, without them we would have never been heard about our daughter's condition.

PANS PANDAS UK is a wonderful light at the end of the darkness for people everywhere.

A charity that shouldn't have to exist but changes the course of so many young lives for the better. Truly a lifeline.

Incredible charity who have literally saved my daughter's life. They are small but do amazing work.

We feel seen amongst this community and appreciate the knowledge shared by the charity. When nobody understands, the NHS, schools, PANS PANDAS UK are there.

My little girl suffered so badly for 2 years until we found the PANS/PANDAS charity and community. We are now just starting treatment after and have hope that things are starting to get better for us as a family. Thanks to the information and invaluable support from this charity.

This charity is so valuable in its support for those suffering with this condition and their families. It can be truly the only support that some families get. Their work is invaluable

The PANS PANDAS UK organization is changing lives.

Absolute angels on earth!

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 2023 to 5 April 2024. We use a financial software package called Xero to manage and monitor our financial transactions, as it is a piece of software compatible with HMRC requirements, and familiar to our Auditors.

8.2 Our Accounts and Bankers

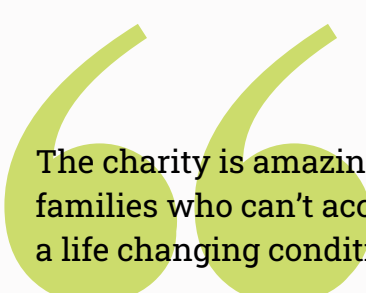
PPUK operates using two bank accounts, as follows:

- Santander Business Account
- Unity Trust Bank Business Account

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

Last year, we had to restructure our operational team to redistribute tasks from a Chief Executive Officer to a small number of part-time (paid) officers. This action was necessary to avoid losses in the year, and a corresponding drain on our reserves. This year (2023/24) has been the first full year of the new operational arrangements. Our actions have successfully restored the financial health and sustainability of the charity, following a period of building our reserves to an acceptable level (see 8.4 below). Now that financial stability has been restored, we can look forward to focussing all of our expenditure on charitable activities.

Our financial results have been independently inspected by our auditors, and there are no issues of any concern. The independent report has been submitted to the Charity Commission alongside our accounts, and the results in detail can be inspected there. The figures contained in those reports are accurate to the penny, but the tables on the following pages present the results in a rounded form to simplify understanding.



The charity is amazing and is helping so many families who can't access help. PANS PANDAS is a life changing condition.

TABLE 8.3.1 : Income Breakdown		
Source of Income	Amount (Rounded)	%
Donations	£63,287	43.5%
Events	£64,248	44.2%
Gift Aid	£16,606	11.4%
Other	£1,220	0.8%
Total Income (Exact)	£145,355	100%

TABLE 8.3.2: Expenditure Breakdown		
Allocation of Expenditure	Amount (Rounded)	%
Health Services Development	£22,327	20.9%
Education Development	£24,765	23.2%
Patient Information and Support	£14,295	13.4%
Youth Advisory Board	£880	0.8%
Research	£5,000	4.7%
Sub Total on Charitable Activities	£67,267	63.1%
Cost of Generating Funds	£28,129	26.4%
Governance	£11,191	10.5%
Total Expenditure (Exact)	£106,587	100%

TABLE 8.3.3 Surplus / Loss on the year

	Amount
Total Income	£145,355
Total Expenditure	£106,587
Total Surplus on year	£38,768

TABLE 8.3.4 Reserves held as at April 5th, 2024

Reserves held as at April 5th, 2023	£38,269
Surplus on year	+ £38,768
Reserves held as at April 5th, 2024	£77,037
Of which held in restricted funds	£0
Of which held in unrestricted funds	£77,037
Reserves as a proportion of annual turnover	52.9% (6.4 months)

Amazing support group. The charity are so helpful. So knowledgeable and supportive. I'm not sure how we'd have coped with this debilitating illness without the advice from them. The website and resources are fantastic too.

PANS/PANDAS UK

RECEIPTS AND PAYMENTS ACCOUNTS
for the Year Ended 5th April 2024

	Notes	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Income from:							
Donations & legacies	2	144,134	-	144,134	72,187	4,000	76,187
Other trading activities		406	-	406	86	-	86
Other		815	-	815	51	-	51
Total income		145,355	-	145,355	72,324	4,000	76,324
Expenditure on:							
Charitable activities:							
Health services development	3	22,328	-	22,328	23,186	-	23,186
Education development		24,765	-	24,765	18,899	4,000	22,899
Patient information and support		14,295	-	14,295	30,727	-	30,727
Youth Advisory Board		880	-	880	-	-	-
Research		4,368	632	5,000	-	5,000	5,000
Total charitable activities		66,636	632	67,268	72,812	9,000	81,812
Raising funds	4	28,128	-	28,128	21,025	-	21,025
Governance	5	11,191	-	11,191	17,197	-	17,197
Total expenditure		105,955	632	106,587	111,034	9,000	120,034
Net income/(expenditure)		39,400	(632)	38,768	(38,710)	(5,000)	(43,710)
Transfers between funds	10	24,669	(24,669)	-	-	-	-
Net movement in funds	9	64,069	(25,301)	38,768	(38,710)	(5,000)	(43,710)
Fund balances brought forward		12,968	25,301	38,269	51,678	30,301	81,979
Fund balances carried forward		77,037	-	77,037	12,968	25,301	38,269

PANS/PANDAS UK

BALANCE SHEET
As at 5th April 2024

	Note	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Current assets							
Debtors		-	-	-	-	-	-
Cash at bank and in hand		77,122	-	77,122	12,968	25,301	38,269
Total current assets		77,122	-	77,122	12,968	25,301	38,269
Current liabilities							
Creditors	8	(85)	-	(85)	-	-	-
Net current assets		77,037	-	77,037	12,968	25,301	38,269
Total assets less current liabilities	9	<u>77,037</u>	<u>-</u>	<u>77,037</u>	<u>12,968</u>	<u>25,301</u>	<u>38,269</u>

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Year Ended 5th April 2024

1. ACCOUNTING POLICIES

a) Basis of preparing the financial statements

PANS/PANDAS UK is a Charitable Incorporated Organisation registered in England & Wales and Scotland. The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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 issued in October 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102), the Charities Act 2011, Charities Accounts (Scotland) Regulations 2006 and UK Generally Accepted Practice.

The financial statements are prepared on a going concern basis under the historical cost convention and are presented in sterling which is the functional currency of the charity and rounded to the nearest £1.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

b) Income & expenditure

All income and expenditure is recognised in the Statement of Financial Activities on the Receipts and Payments Basis and therefore only recognised once the charity receives or expends the funds. Expenditure has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to such headings, they have been allocated on a basis consistent with the use of resources (see 1.c) below).

c) Allocation of expenditure

Salaries - The salaries of project workers are allocated directly to the projects on which they work, alongside the charity's contribution to pensions where appropriate.

Other costs - Core costs are allocated to the expenditure headings in the Statement of Financial Activities as follows:

	Administration Costs %	Communications Costs %
Health services development	30	20
Education development	30	20
Patient information and support	30	20
Youth Advisory Board	0	0
Research	0	0
Cost of generating funds	5	40
Governance	5	0
	100	100
	Administration Costs £	Communications Costs £
Health services development	5,322	1,052
Education development	5,322	1,052
Patient information and support	5,321	1,051
Youth Advisory Board	-	-
Research	-	-
Cost of generating funds	887	2,103
Governance	887	-
	17,739	5,258

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Year Ended 5th April 2024

1. ACCOUNTING POLICIES - continued

d) Taxation

The charity is exempt from tax on its charitable activities.

e) 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.

f) Creditors payable within one year

The charity runs a credit/charge card account with Lloyds Bank PLC; this figure reflects the outstanding balance at the year end. There are no other debts.

g) 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 as expended.

2. DONATIONS AND LEGACIES INCOME

	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Regular giving	3,163	-	3,163	3,269	-	3,269
Major donors	15,307	-	15,307	-	-	-
Individuals	23,316	-	23,316	21,012	-	21,012
Companies/Organisations	21,494	-	21,494	10,884	-	10,884
Trusts & foundations	-	-	-	-	4,000	4,000
In memoriam	-	-	-	170	-	170
PPUK fundraising events	6,386	-	6,386	770	-	770
Community-led events	57,862	-	57,862	26,443	-	26,443
Gift Aid	16,606	-	16,606	9,639	-	9,639
Total donations and legacies	144,134	-	144,134	72,187	4,000	76,187

3. CHARITABLE ACTIVITIES EXPENDITURE

	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Project costs	12,790	632	13,422	17,022	5,000	22,022
Project staff costs	34,726	-	34,726	48,365	4,000	52,365
Administration*	15,965	-	15,965	4,156	-	4,156
Communications*	3,155	-	3,155	3,269	-	3,269
Total expenditure on charitable activities	66,636	632	67,268	72,812	9,000	81,812

* = see Note 1.c)

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Year Ended 5th April 2024

4. COSTS OF GENERATING FUNDS

	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Merchandise	48	-	48	-	-	-
Resources & materials	1,279	-	1,279	1,320	-	1,320
Event costs	7,699	-	7,699	1,720	-	1,720
Platform fees	3,063	-	3,063	1,435	-	1,435
Professional fees	12,360	-	12,360	8,600	-	8,600
Other fundraising costs	20	-	20	46	-	46
Staff costs	669	-	669	6,260	-	6,260
Administration*	887	-	887	554	-	554
Communications*	2,103	-	2,103	1,090	-	1,090
Total expenditure on raising funds	28,128	-	28,128	21,025	-	21,025

* = see Note 1.c)

5. GOVERNANCE COSTS

	2024 Unrestricted £	2024 Restricted £	2024 Total £	2023 Unrestricted £	2023 Restricted £	2023 Total £
Staff costs	-	-	-	8,689	-	8,689
Trustee expenses/costs	1,604	-	1,604	2,202	-	2,202
Insurance	832	-	832	775	-	775
Accountancy software	384	-	384	361	-	361
Bookkeeping	4,212	-	4,212	3,116	-	3,116
Independent examiner	2,040	-	2,040	1,164	-	1,164
HR services	1,232	-	1,232	-	-	-
Other costs	-	-	-	59	-	59
Administration*	887	-	887	831	-	831
Total governance costs	11,191	-	11,191	17,197	-	17,197

* = see Note 1.c)

6. STAFF COSTS

	2024 £	2023 £
Gross wages	45,764	60,519
Social security costs	-	1,915
Pension costs	1,270	2,128
Total salaries, wages and related costs	47,034	64,562

PANS/PANDAS UK

NOTES TO THE ACCOUNTS for the Year Ended 5th April 2024

7. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 5th April 2024 nor for the year ended 5th April 2023.

Trustees' expenses

The following expenses were reimbursed to trustees:

	2024 £	2023 £
Travel, subsistence and accommodation	1,572	2,138
Printing, postage and stationery	-	71
	<u>1,572</u>	<u>2,209</u>

8. CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR

	2024 £	2023 £
Credit/charge card	85	-
	<u>85</u>	<u>-</u>

9. MOVEMENT IN FUNDS

	Funds at 06.04.23 £	Incoming resources £	Expended resources £	Transfers £	Funds at 05.04.24 £
Unrestricted (General) fund	12,968	145,355	(105,955)	24,669	77,037
Restricted funds:					
Research Fund	25,301	-	(632)	(24,669)	-
	<u>25,301</u>	<u>-</u>	<u>(632)</u>	<u>(24,669)</u>	<u>-</u>
TOTAL FUNDS	<u>38,269</u>	<u>145,355</u>	<u>(106,587)</u>	<u>-</u>	<u>77,037</u>

	Funds at 06.04.22 £	Incoming resources £	Expended resources £	Transfers £	Funds at 05.04.23 £
Unrestricted (General) fund	51,678	72,324	(111,034)	-	12,968
Restricted funds:					
Education Fund	-	4,000	(4,000)	-	-
Research Fund	30,301	-	(5,000)	-	25,301
	<u>30,301</u>	<u>4,000</u>	<u>(9,000)</u>	<u>-</u>	<u>25,301</u>
TOTAL FUNDS	<u>81,979</u>	<u>76,324</u>	<u>(120,034)</u>	<u>-</u>	<u>38,269</u>

PANS/PANDAS UK

**NOTES TO THE ACCOUNTS
for the Year Ended 5th April 2024**

10. TRANSFERS BETWEEN FUNDS

With the agreement of The Charity Commission, £24,669 of the £25,301 held as restricted to medical research at the beginning of the year were re-designated as unrestricted. The balance of £632 was spent in accordance with the original restriction. Thus, at year end the charity held no restricted funds.

11. 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.

12. RELATED PARTY DISCLOSURES

There were no related party transactions during the year.

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 the Charity for the year ended 5th April 2024.

Responsibilities and basis of report

As the charity's trustees 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 charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

I have completed my examination. I confirm that no material matters have come to my attention in connection with the examination giving me cause to believe that in any material respect:

1. accounting records were not kept in respect of the charity as required by section 130 of the Act; or
2. the accounts do not accord with those records.

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Steven Mugglestone BA (Hons) FCA

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

Date: 19th July 2024

8.4 Policies on Reserves

During 2023/24, the Charity developed a formal risk-based approach to the level of reserves we hold, in both restricted and unrestricted funds.

The charity took the view that the absolute minimum reserve would be just sufficient only to meet our contracted expenditure requirements. This was not regarded as a sustainable position.

The quantitative work considered several plausible risks regarding income loss, and expenditure increases, together with a view on how long the charity could continue its charitable activities. These assessments resulted in a figure representing about 6 months turnover. Given also that the guidance from the Charity Commission on an appropriate level of reserves is in the order of 6 months for a charity of this size, the trustees took the view that 6 months is an appropriate level.

This level has been achieved, and, moving forward, the charity can focus its efforts on charitable activities rather than asset building. It is also, of course, necessary to note that the charity is not building reserves for its own sake, but solely as a sustainable response.

The charity was, in 2023/24, successful in persuading people and organisations who had historically provided restricted funds, that these should be converted into unrestricted funds. The Charity Commission provided guidance, and later endorsement, of allowing the derestriction. All the charity's funds are now unrestricted and can be flexibly used.

While the year of 2023/24 saw a deliberate attempt to rebuild reserves following the organisational re-arrangements described earlier, the next year, 2024/25, will allow the charity to focus all its efforts on charitable activities.

8.5 Funds in deficit

The charity has no 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

11.1 Financial Year 2024/25

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 2024/25.

11.1.1 Rebrand and launch of new website

The new PPUK website will be launched in June 2024. Many of our community are unable to locate our resources easily on our website, and so it was agreed that we would focus on ensuring our new website is accessible with a search function. We anticipate that the new website will enable people to find what they need more easily. The new website integrates with our CRM and finance systems which will enable us to work more productively.

11.1.2 Build relationships with our international counterparts

As a member of the board of EXPAND (the European umbrella organisation representing all patient communities within Europe), we have good relationships with our European counterparts, but in 2024/25 we would like to reach out to the wider International PANS peers and work together to develop PANS and PANDAS acceptance worldwide.

11.1.3 PANS Awareness Day 2024

We hope to make an international splash on PANS Awareness Day this year, by bringing together all the European and International patient communities, charities and organisations in a unified awareness campaign on 9th October 2024.

11.1.4 Youth Advisory Board regional family fun days

We were hoping to hold a family fun day led by our Youth Board last year, however due to illness, this had to be postponed, and so plans are underway to host a series of regional family fun days during the summer of 2024 in line with the Youth Board preferences.

11.1.5 Volunteer Strategy

PPUK is fortunate to have support from a large and engaged community and we are often asked for volunteering opportunities. We hope to develop a volunteer strategy during 2024/25 so that we may utilise and support our eager and dedicated volunteers.

11.1.6 Launch a 'Friends of PANS PANDAS UK' scheme

PPUK is not a membership organisation, currently count the members of our Facebook support group as our community, although this does not give us accurate information about our community. Work on a Friends of PPUK scheme is underway and we plan to launch during the autumn of 2024, to enable us better support, reach and understand our community and identify more accurately how many people we are supporting.

11.1.7 Host a two-day conference

Working with the University of Leicester Medical School, plans are in motion to host a 2-day conference during 2026. Day one will be aimed at medical professionals, and day 2 will be for our community. We look forward to releasing more information soon.

11.1.8 Attend the Royal College of General Practitioners Annual Conference in October 2024

We will attend the Royal College of Practitioners Annual Conference in Liverpool in October 2024 in order to continue to raise awareness of the conditions and alert GPs to the forthcoming publication of the clinical guideline. Attendees of this conference are the gatekeepers of the NHS and they have a pivotal role to play in spotting the early signs of PANS and PANDAS, investigating, making appropriate referrals and providing ongoing care and support to the family post-diagnosis. We will mirror the approach we took to the RCPCH conference and attend as a blended model of staff and volunteers.

11.1.9 Attend a number of Educational Conferences

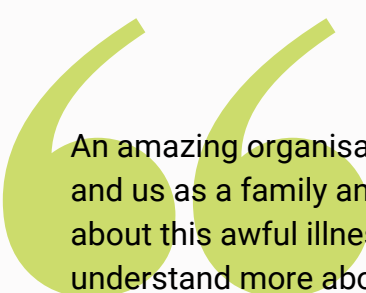
We will attend the NASEN (National Association for Special Educational Needs) Educational Conference in July 2024, present and deliver education workshops at Birmingham Newman University and Manchester Metropolitan University and participate in the Discover Inclusion Online Conference October and attend the TES SEND show both in October 2024.

11.1.10 Council for Disabled Children

We will deliver a presentation on PANS and PANDAS to the Council for Disabled Children in London in September 2024.

11.1.11 PPSG Education, Health and Social Care Statement

We will create and disseminate the Education, Health and Social Care working group position statement about PANS and PANDAS relevant for education, social care and health professionals.



An amazing organisation which has supported our son and us as a family and is continuing to help us find out about this awful illness. This organisation helps us understand more about how we can find a way of managing PANS/PANDAS and keeps a community informed and in communication with each other to find a way together

11.1.12 Teacher Training

We will further develop the teacher training for more specialised educators and to increase the reach of the training.

11.1.13 Guideline Development

We will continue to drive forward the guideline development work, working closely with the co-chairs to ensure that there is co-production throughout the process.

11.1.14 Strategic Partnerships

We will continue to develop new (and nurture existing) strategic partnerships with fellow charities, parent organisations and strategic alliances to ensure that the PANS and PANDAS community is recognised and represented in all relevant areas.

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 2023 to 5th April 2024.

Signed:



Name:

Vicky Burford

Position:

Chair of Trustees, PANS PANDAS UK

Date:

19th July 2024

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



Accounts



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

[Section 4:](#) Reference and Administrative Details

[Section 5:](#) Structure, Governance and Management

[Section 6:](#) Objectives and Activities

[Section 7:](#) Achievements and Performance

[Section 8:](#) Financial Review

[Section 9:](#) Funds Held as Custodian Trustee on Behalf of Others

[Section 10:](#) Public Benefit Statement

[Section 11:](#) Plans for Future Periods

[Section 12:](#) Signed Statement

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



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.

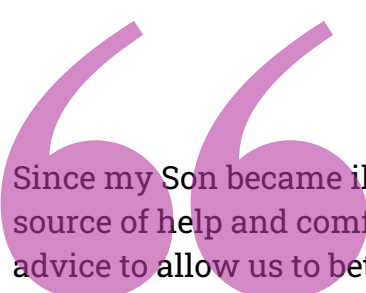
Section 6: Objectives and Activities

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

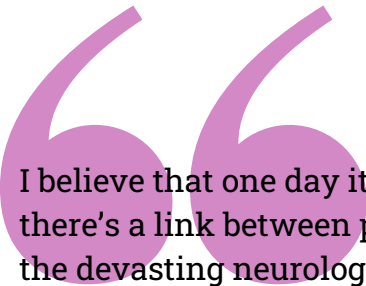
A series of useful and informative expert led webinars were developed for the PPUK community. The majority of these webinars are now available on the website and available for those who were unable to attend the sessions live.

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

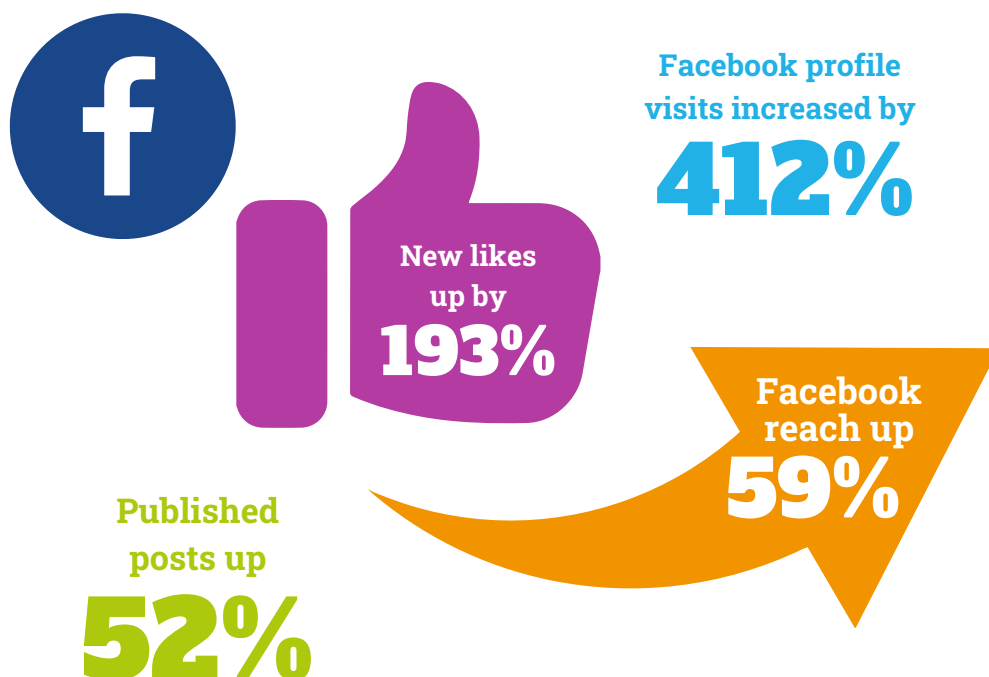
As part of the fundraising plan, PPUK installed 'Donorfy' (a fundraising CRM programme) which helped to more effectively manage fundraising campaign record-keeping and enable a better stewardship of donors and fundraisers going forward.

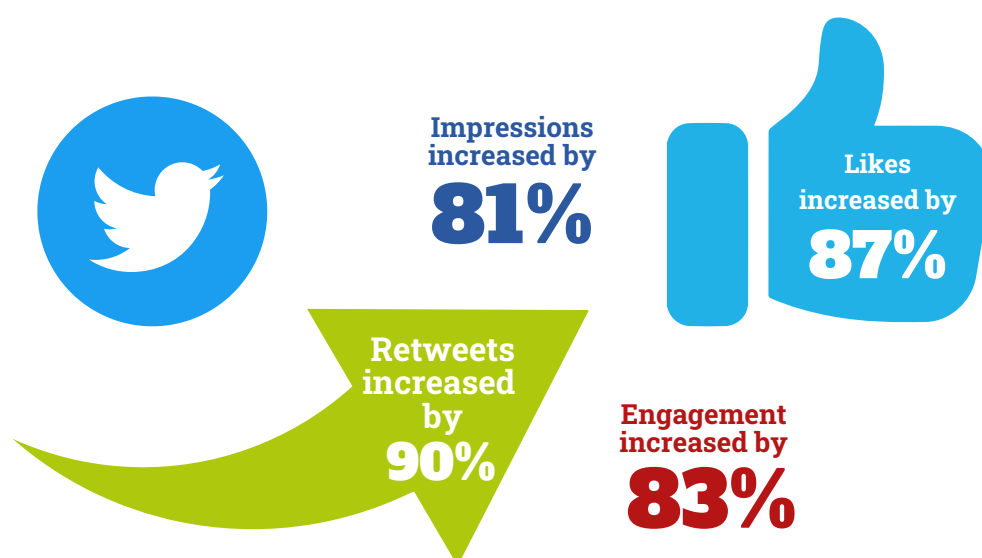
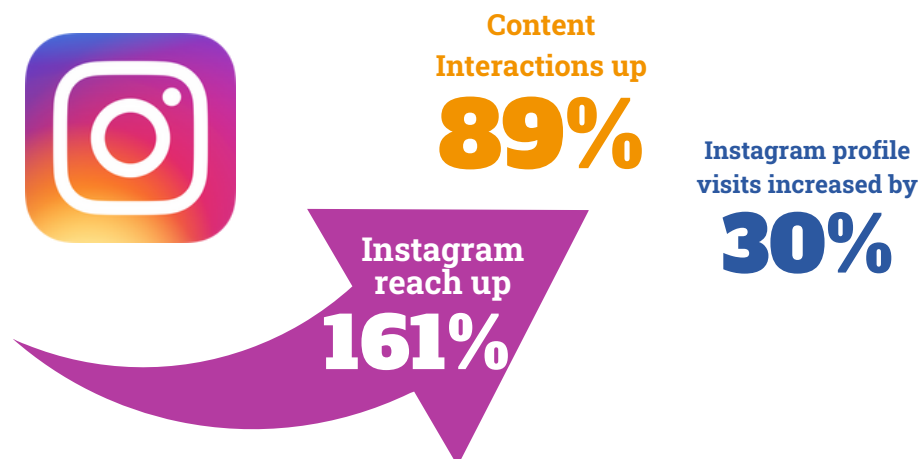
6.2.20 Safeguarding Survey

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.

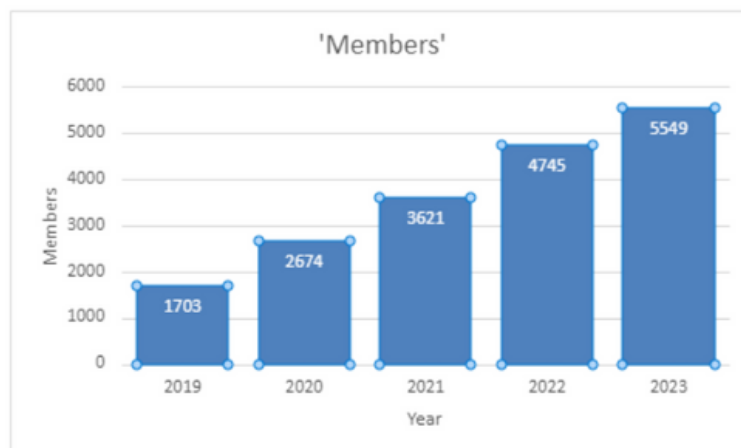
PPUK's mission to promote understanding and awareness of PANS and PANDAS in order to support the health and wellbeing of everyone impacted by these conditions in the UK.

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%

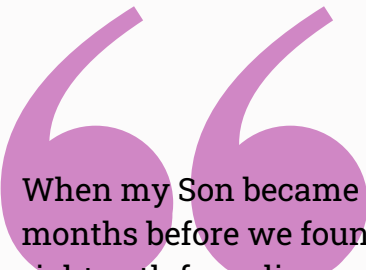
Table 8.3.3 presents the profit / loss on the year.

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

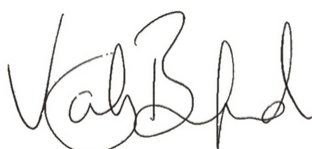
11.11 Safeguarding and FII Guide for Professionals

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

**CONTENTS OF THE FINANCIAL STATEMENTS
for the Year Ended 5 April 2023**

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Statement of Financial Activities	3
Balance Sheet	4
Notes to the Financial Statements	5 to 8
Detailed Statement of Financial Activities	9

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

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: 20th 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 £
INCOME AND ENDOWMENTS FROM					
Donations and legacies		<u>72,324</u>	<u>4,000</u>	<u>76,324</u>	<u>90,480</u>
EXPENDITURE ON					
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	
Total charitable activities		81,812		81,812	54,646
Cost of generating funds		21,025		21,025	
Governance		17,198		17,198	8,474
Total		<u>111,035</u>	<u>9,000</u>	<u>120,035</u>	<u>63,120</u>
NET INCOME/(EXPENDITURE)	5	(38,711)	(5,000)	(43,711)	27,360
RECONCILIATION OF FUNDS					
Total funds brought forward		<u>51,678</u>	<u>30,301</u>	<u>81,979</u>	<u>54,619</u>
TOTAL FUNDS CARRIED FORWARD	5	<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>

The notes form part of these financial statements

PANS / PANDAS UK

BALANCE SHEET
5 April 2023

	Notes	Unrestricted fund £	Restricted funds £	5.4.23 Total funds £	5.4.22 Total funds £
CURRENT ASSETS					
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>
NET CURRENT ASSETS		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
TOTAL ASSETS LESS CURRENT LIABILITIES		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
NET ASSETS		<u>12,967</u>	<u>25,301</u>	<u>38,268</u>	<u>81,979</u>
FUNDS	5				
Unrestricted funds				<u>12,967</u>	51,678
Restricted funds				<u>25,301</u>	<u>30,301</u>
TOTAL FUNDS				<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 £
INCOME AND ENDOWMENTS FROM			
Donations and legacies	<u>77,703</u>	<u>12,777</u>	<u>90,480</u>
 EXPENDITURE ON			
Charitable activities	47,847	6,799	54,646
Charitable activities			
Governance	<u>8,474</u>	<u>-</u>	<u>8,474</u>
Total	<u>56,321</u>	<u>6,799</u>	<u>63,120</u>
 NET INCOME	21,382	5,978	27,360
 RECONCILIATION OF FUNDS			
Total funds brought forward	<u>30,296</u>	<u>24,323</u>	<u>54,619</u>
 TOTAL FUNDS CARRIED FORWARD	<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
 TOTAL FUNDS	<u>81,979</u>	<u>76,324</u>	<u>(120,035)</u>	<u>(43,711)</u>	<u>38,268</u>

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

5. MOVEMENT IN FUNDS - continued

COMPARATIVE FOR PREVIOUS PERIOD 2021-22	Funds at 6.4.21 £	Incoming resources	Expended resources	Net movement in funds	Funds at 5.4.22 £
<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
TOTAL FUNDS	54,619	90,480	(63,120)	27,360	81,979

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 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	76,238	90,340
Merchandise	<u>86</u>	<u>140</u>
	76,324	90,480
Total incoming resources	76,324	90,480
EXPENDITURE		
Charitable activities		
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>
	81,813	44,909
Support costs		
Cost of generating funds		
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>
	21,025	9,737
Governance costs		
Staff costs	8,689	3,633
Admin costs	831	700
Governance costs	<u>7,677</u>	<u>4,141</u>
	17,197	8,474
Total resources expended	120,035	63,120
Net (expenditure)/income	<u>(43,711)</u>	<u>27,360</u>

**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: 20th October 2023

Accounts



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

[Section 4:](#) Reference and Administrative Details

[Section 5:](#) Structure, Governance and Management

[Section 6:](#) Objectives and Activities

[Section 7:](#) Achievements and Performance

[Section 8:](#) Financial Review

[Section 9:](#) Funds Held as Custodian Trustee on Behalf of Others

[Section 10:](#) Public Benefit Statement

[Section 11:](#) Plans for Future Periods

[Section 12:](#) Signed Statement

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 light blue 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

**CONTENTS OF THE FINANCIAL STATEMENTS
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
	90,480	50,726
Total incoming resources	90,480	50,726
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	-
	63,120	18,522
Total resources expended	63,120	18,522
Net income	27,360	32,204

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

Accounts

Year ending 5 April 2021

Annual Report 2020/21

PANS PANDAS UK

Introduction

As Charity Secretary, I am pleased to present the Annual Report for 2020-21 for PANS PANDAS UK.

As a charity, PANS PANDAS UK is required to prepare an Annual Return, as the Charity's gross income in the financial year exceeded £10,000.

The aim of this report is to explain, in plain English, what the Charity has achieved, and how its income has been spent.

The report also helps the Charity Commission to make sure that the details it holds are as complete and accurate as possible. The Annual Return gives the Commission basic financial details, and details of contacts, trustees, activities and of the charity's classification.

This report is laid out in the following manner:

Section 1: What are PANS and PANDAS, and What is PANS PANDAS UK?	3
Section 2: This Annual Report - General	3
Section 3: Meeting Our Legal Requirements	3
Section 4: Reference and Administrative Details	4
Section 5: Structure, Governance and Management	5
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Section 7: Achievements and Performance	10
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Section 9: Funds Held as Custodian Trustee on Behalf of Others	14
Section 10: Public Benefit Statement	14
Section 11: Plans for Future Periods	14
Section 12: Signed Statement	16

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 conditions which result in inflammation of the brain, causing a variety of neuro-psychiatric conditions such as OCD, tics and eating disorders.

PANS PANDAS UK (called “we” or “us”) is a UK-wide Charity which was established by a dedicated and determined group of parents with children who are affected by PANS or PANDAS. PANS PANDAS UK commenced work as an organisation in 2017 creating a network of doctors and the PANS Physicians Network Meeting, setting up the Facebook support group, website, etc. Charity status was achieved on 22 May 2018.

PANS PANDAS UK was formed in order to raise awareness and understanding of these conditions amongst the general public and medical professionals. It is our mission to ensure that the conditions are known about in every GP Surgery, every school and every hospital, so every child can receive an early diagnosis and effective treatment. We are working closely with a network of doctors in order to ensure better diagnosis and early effective treatment for those suffering with these little-understood, but life-changing conditions.



Please visit our website for more information:
www.panspandasuk.org

Section 2: This Annual Report - General

This Annual Report 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 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 Secretary, whose name and address are as follows:

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, 41 Somerset Road, Ryde, Isle of Wight, PO33 1BU.

Secretary: Mrs Vicky Burford, Lowfields, Long Itchington Road, Offchurch, Leamington Spa, CV33 9AY.

Treasurer: Mr Philip Edwin Hall, 11, Fernhill Drive, Leamington Spa, CV32 4JX.

Adult Lead: Cindy Hvid, 78, Camilla Road, London, SE16 3NJ.

Advocacy Lead: Zoe Van Den Bosch, 113 Shortlands Road, Kingston, Surrey, KT2 6HF.

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 Trustee meetings, held on a video-conference basis, or physically meeting if necessary. The minutes of the meeting are formally recorded by the Secretary.

Section 6: Objectives and Activities

6.1: The Purposes of the Charity

PANS PANDAS UK was formed in order to raise awareness and understanding of PANS and PANDAS amongst the general public and medical professionals. It is our mission to ensure that the conditions are known about in every GP Surgery, every school and every hospital, so every child can receive an early diagnosis and effective treatment. We are working closely with a network of doctors in order to ensure better diagnosis and early effective treatment for those suffering with these little-understood, but life-changing conditions.

During the year, the Charity's objectives and constitution were extended in order to allow us to act as Advocates between families and medical professionals. The adopted wording is: "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 the third AGM in June 2019;
- Continued to grow the PANS Physician's Network UK (PPN UK);
- Raised just over £50,000 in fundraising activities;
- Launched the 2021 Parent Survey;
- Held a number of All-Party Parliamentary Group (APPG) meetings;
- Put in pre-application for NICE Guidelines;
- Put in application for SIGN Guidelines;
- Appointed an Advocacy Lead to grow the service;
- Appointed an Education Executive to grow the resources for schools;
- Delivered a webinar for teachers, SENCOS and school nurses;
- Developed a number of new awareness videos;
- Funded research projects;
- Commissioned the writing of a UK-focused PANS and PANDAS book;
- Appointed a Young Ambassador;
- Held an Inaugural meeting with the BPNA Research Priority Group;
- Appointed a Media Executive to develop a media presence.

6.2.1: Held the Third AGM

The AGM was held in June 2020 via Zoom due to the Coronavirus Pandemic.

The Trustees of the charity were joined by 29 individuals and despite some initial technical teething problems, the meeting was a success.

6.2.2: PANS Physician's Network UK (PPN UK)

The PANS Physician's Network UK is a network of medical professionals from different specialities including neurology, immunology, psychiatry, paediatrics and general practice who meet on a quarterly basis to understand PANS and PANDAS better by sharing experiences, treatment successes, discussing anonymous cases and undertaking training.

The meetings ran successfully via Microsoft Teams and we saw a greater number of medical professionals attending, which we put down to the fact that travel is no longer necessary in order to attend.

6.2.3 Fund Raising amounted to over £50,000

PANS PANDAS UK has been extremely fortunate to receive a large number of generous donations and been the recipients of many fundraising activities during 2020/2021.

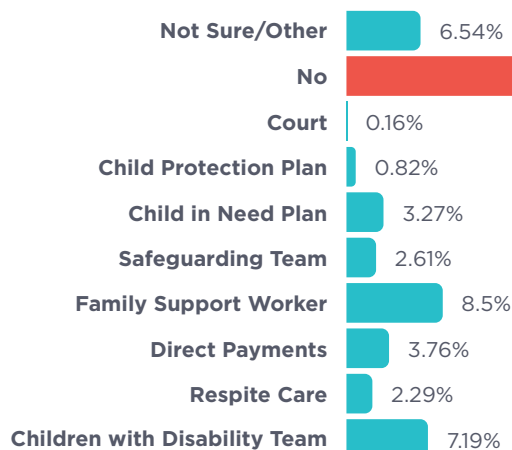
PANS PANDAS UK instigated its first-ever charity-led fundraising campaign in 2020 by taking part in The Big Give's Christmas Challenge. Over £30,000 was raised during this fundraiser alone. Fund-raising is accounted for by individuals' contributions (£19,349) and by external fund-raising activities (£31,140).

6.2.4: Parent Survey

Our second annual parent survey was launched in March 2021 and was completed by 707 members. The comprehensive results will be published very soon, but some of the key data from this questionnaire can be seen below.

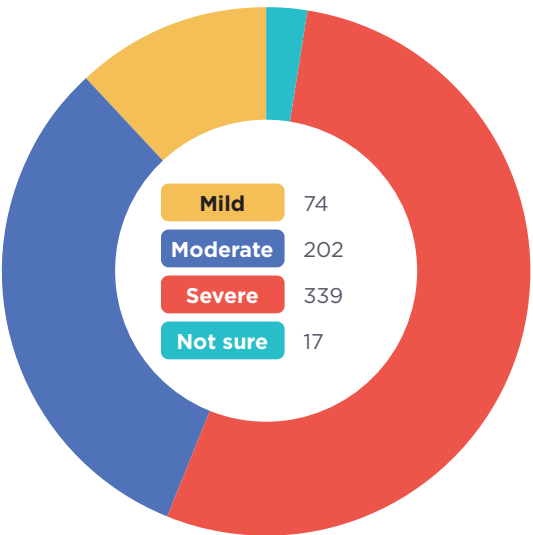
What social care support have you received?

612 respondents

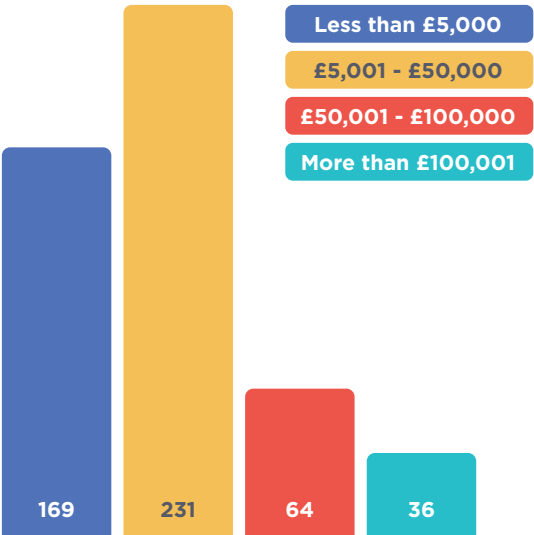


80% of families
have not received any
social care support

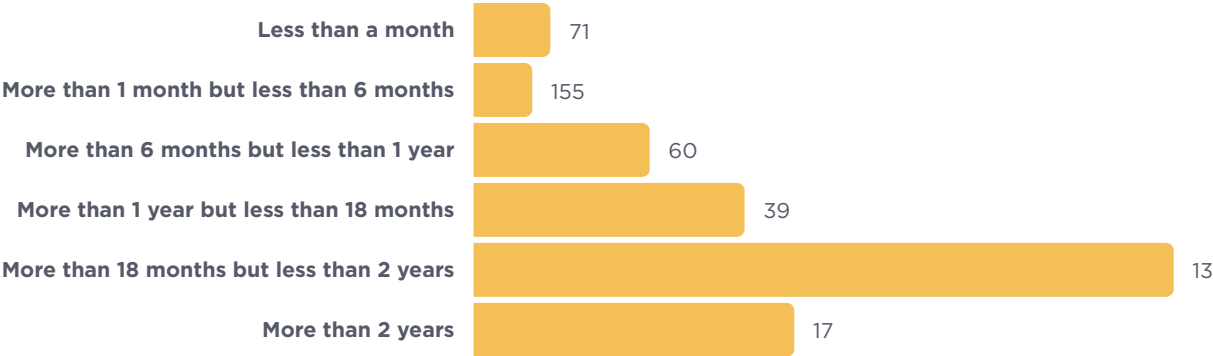
How would you rate the severity of your child's symptoms at onset



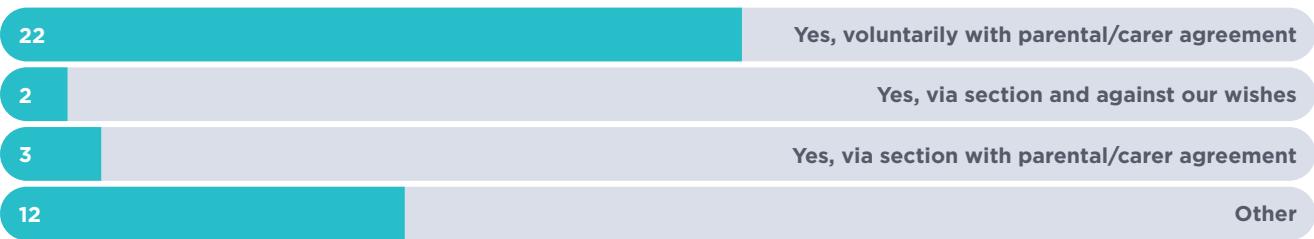
What is the total estimated financial impact due to your child's illness?



How long did you wait between referral and your first CAMHS appointment? 327 respondents



Has your child ever been admitted to an inpatient or psychiatric institution?



6.2.5: All Party Parliamentary Group (APPG)

The PANS PANDAS All Party Parliamentary Group comprises a number of MP's who, despite the challenges faced due to the pandemic, have been able to meet virtually on a number of occasions. These MPs, alongside peers, parent representatives, a respected PPN Doctor and the Charity come together in order to further the PANS PANDAS UK objective 'Using an integrated inquiry-based approach against relevant legislation, policy and evidence base, reconcile the variation in the detection, diagnosis and provision of treatment of PANS and PANDAS in the UK' For and on behalf of the thousands of families their children and adults.

6.2.6: Pre-application for NICE Guidelines

NICE is the National Institute for Health and Care Excellence and is the body responsible for producing treatment guidelines for the NHS. As a result of the successful APPG meetings and actions taken by the member MPs outlined above, PANS PANDAS UK has been invited to submit an application for NICE Guidelines. The pre-application has been submitted and we are waiting on a response before progressing to the next stage.

6.2.7: Application for SIGN Guidelines

SIGN is an acronym for Scottish Intercollegiate Guidelines Network and it is the body responsible for producing treatment guidelines in Scotland. A further result of the successful APPG meetings and actions taken by the member MPs is that PANS PANDAS UK has submitted an application for SIGN Guidelines. The application has gone to a decision meeting which is taking place in May 2021.

6.2.8: Appointed an Advocacy Lead to grow the service

Following the addition of Advocacy to the Charity's objectives, PANS PANDAS UK has appointed an experienced Advocacy Lead with the intention of growing the advocacy service.

6.2.9: Appointed an Education Executive to develop the resources for schools

PANS PANDAS UK appointed an experienced Education Executive to grow a team and develop support resources for schools and support for parents seeking an Educational Health Care Plan (EHCP). An EHCP is a document created in order to identify and state the particular support that must be given to an individual child with additional educational needs. The Education Executive has created various resources for both schools and parents in order to support children in the classroom. CPD-Accredited training is also being written in order to further support educators when dealing with pupils and students suffering with symptoms of PANS and PANDAS.

6.2.10: Hosted a webinar for schools

One of the first tasks undertaken by our Education Executive was to put on a webinar for educators, special educational needs Co-ordinators (SENCO's), school nurses and educational psychologists. Attended by over 100 delegates the webinar is available on our website.

6.2.11: Awareness Videos

PANS PANDAS UK released a selection of awareness videos during 2020 and the early part of 2021. These videos can be seen on our website or our YouTube Channel.

6.2.12: Funded Research Projects

PANS PANDAS UK is delighted to have been asked to fund a research project looking at identifying organic markers for Obsessive Compulsive Disorder (OCD). The project is currently undergoing ethical approval and will commence once approval is awarded.

6.2.13: Book

A book is being written which aims to cover all areas of PANS and PANDAS. It is anticipated that it will take the form of a 'Guide to PANS and PANDAS' and will be illustrated with real-life stories from individuals who have experienced PANS or PANDAS.

6.2.14: Young Ambassador

PANS PANDAS UK is pleased to have a Young Ambassador on board. Romy Worthington who has a presence on social media and YouTube under the name 'Ticcer's Unite' has agreed to represent the charity to its younger members and has already made her mark, working with our media Executive and raising our Twitter, YouTube, Snapchat and TikTok profiles.

6.2.15: British Paediatric Neurological Association (BPNA) Research Priority Group

The British Paediatric Neurological Association (BPNA) is the professional organisation for doctors who specialise in the care of children with neurological disorders.

PANS PANDAS UK met the BPNA Research Priority Group representatives in 2021 and will be working with them to identify a research question in order to progress with some research, hopefully starting in 2022.

6.2.16: Developing Media Presence

Since appointing our Media Executive, the media profile of PANS PANDAS UK has gone from strength to strength, with appearances by our members on Channel 4's 'Steph's Packed Lunch' and various local BBC radio interviews. Dr Sarah Jarvis discussed the topics on BBC Radio 2's Jeremy Vine show. All interviews can be accessed via our website.

Social media awareness is rising too as a result of the parents from the support group tweeting various celebrities, scientists, medical professionals and MP's.

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

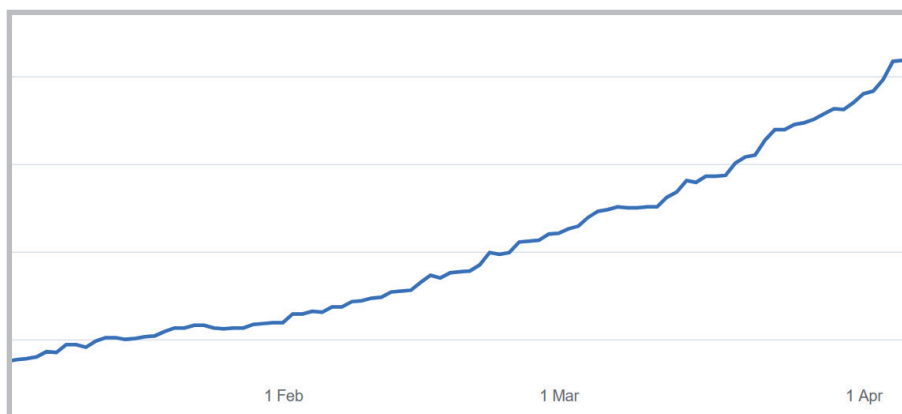
We report on our performance and achievements on several measures.

7.1: Our Main Mission

Our main mission is to ensure that PANS and PANDAS are known about 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 3,621 members of the PANS PANDAS UK Support Group and 208 Members of the PANS PANDAS UK Support Group for Adults.



7.3: Service User Feedback

Here is some feedback the charity has received from individuals they have been able to support and some members of the online support group.

"So grateful for all you do. In 2012 when this illness started for us there was nothing, no charity, no official voice. To see where we are now because of you guys is amazing. I am so grateful for the charity and for all of you who put so much energy into it xxx"

"So happy to have found the charity. Months of having no idea what my daughter is suffering. We have a little bit of hope now on the horizon."

"Thank you doesn't seem big enough! But thank you so much for all of the time, heartache, strategy planning and love you put into advocating and trying to save our children."

"Thank you from the bottom of my heart! Honestly don't know where we would be without the support provided by the amazing charity."

"There is so much love care and support in this group, like every precious one in this group I can't thank you enough for all you do. It will be forever appreciated."

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 2020 to 5 April 2021.

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

We have prepared our accounts on a "Receipts and Payments" basis, which means that we have 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.

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 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 auditor has prepared a statement of conformity.



CHARITY COMMISSION
FOR ENGLAND AND WALES

Charity Name :
PANS / PANDAS UK

Charity No:
1178484

CC16a

Receipts and payments accounts

For the period from	06/04/2020	To	05/04/2021
------------------------	------------	----	------------

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	50,489	-	-	50,489	22,751
Conferences	-	-	-	-	-
PANS Physicians' Network	-	-	-	-	-
Exhibitor / Awareness	238	-	-	238	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total (Gross income for AR)	50,727	-	-	50,727	22,751
A2 Asset and investment sales, (see table).					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total receipts	50,727	-	-	50,727	22,751
A3 Payments					
Fund Raising	16,959	-	-	16,959	6,713
Conferences	-	-	-	-	3,865
PANS Physicians' Network	-	-	-	-	2,317
Exhibitor / Awareness	1,563	-	-	1,563	3,896
Transactions for next year's events	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
	-	-	-	-	-
Sub total	18,522	-	-	18,522	16,791
A4 Asset and investment purchases, (see table)					
	-	-	-	-	-
	-	-	-	-	-
Sub total	-	-	-	-	-
Total payments	18,522	-	-	18,522	16,791
Net of receipts/(payments)	32,205	-	-	32,205	5,960
A5 Transfers between funds	-	-	-	-	-
A6 Cash funds last year end	22,415	-	-	22,415	16,455
Cash funds this year end	54,620	-	-	54,620	22,415

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 2021

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
Warwickshire
CV34 4EW

11 June 2021

8.4 Policies on Reserves

We seek to hold a minimum bank balance equating to about 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 describe our plans for the following activities in the financial year 2020/21:

- Continue with APPG and follow up recommendations from MPs;
- Webinar for GP's;
- Continue to expand our media profile;
- Identify doctors to work with PPN UK on adult issues;
- Create a network for functional doctors to run alongside the PPN;
- Create a network for nurses to run alongside the PPN;
- Fund more research in relation to PANS and PANDAS in the UK.

11.1: All-Party Parliamentary Group (APPG)

Following a number of virtual meetings with the APPG, recommendations for next steps remain the same as last year and are outlined below:

- Request that MPs begin an Early Day Motion.
- Gather names of 'sympathetic MPs' to support this motion, with the goal of parliamentary debate.
- Alert relevant media outlets on the progression of the cause and the condition of PANS/PANDAS.
- Have head of Select Committee request a meeting with Jeremy Hunt.
- Request that MPs engage in conversation with Secretary of State for Health and Social Care, Matt Hancock: 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 Department of 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: Information Webinar for GP's

Following the success of the recent Educator's Webinar, PANS PANDAS UK plans to provide an information webinar for GPs. This will be approximately 1 hour in duration and will be free to access.

11.3: Expand on Media Profile and Finalise Documentary

The charity has a group of dedicated journalists, presenters, media and PR representatives who are all keen to work together to raise the profile of PANS and PANDAS. The charity is currently in discussions with a number of journalists and producers who are keen to cover this subject area.

11.4: Identify Doctors to Work with PPN UK on Adults

With the substantial increase in adult sufferers of PANS approaching the charity for support, it has become a priority for PANS PANDAS UK to identify doctors who are prepared to learn about the adult conditions and treat people accordingly.

11.5: Create a network for Functional Doctors to run alongside the PPN (PANS Functional Network)

There are different types of medical practice. Allopathic medicine relates to the kind of medicine we are familiar with from the NHS and when we visit our GP, and it is what might be considered as 'normal' medicine. There is a growing area of medicine known as functional medicine which involves a range of treatments including diet, exercise, herbal treatments and other treatments perhaps not offered via the NHS. Increasing numbers of the families we support are choosing functional medicine over allopathic medicine. PANS PANDAS UK has therefore decided that it would be in the best interests of our members to create a PANS Functional Network to run alongside the PPN UK, in order to share knowledge and experience. It may be at some point in the future that these two meetings will be streamlined into one larger meeting.

11.6: Create a network for Nurses to run alongside the PPN (PANS Nurses Network)

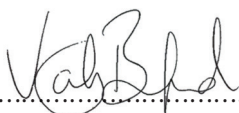
PANS PANDAS UK is receiving more and more enquiries from nurses who are involved in the care of children with these conditions. With this in mind, the Charity felt it was prudent to develop a network for these nurses to run alongside the PPN UK, in order to share knowledge, experience and ideas for moving awareness and treatment forward. It may be at some point in the future that all medical networks will be streamlined into one larger meeting.

11.7: Research

PANS PANDAS UK is keen to develop or identify and fund further research and/or clinical trials within the UK in order to identify the very best course of treatment for individuals affected by these conditions.

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 2020 to 5th April 2021.

Signed: 

Name: Vicky Burford

Position: Secretary, PANS PANDAS UK.

Date: 26 August 2021

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

Document Details:

Filename:	21.06.11 PANS PANDAS UK 2021 Accounts.PDF
Client of:	Michael Harwood & Co

Signature Details

Name:	Vicky Burford
Email:	secretary@panspandasuk.org
Date & Time:	29/07/2021 12:45:36 (BST)
IP Address:	78.145.149.164
Signing Statement:	PANS / PANDAS UK confirms that the information is correct and complete to the best of their knowledge and belief.

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**REPORT OF THE TRUSTEES AND
UNAUDITED FINANCIAL STATEMENTS
FOR THE YEAR ENDED 5 APRIL 2021
FOR
PANS / PANDAS UK**

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

**CONTENTS OF THE FINANCIAL STATEMENTS
for the Year Ended 5 April 2021**

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Independent Examiner's Report	3
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Balance Sheet	5
Notes to the Financial Statements	6 to 8
Detailed Statement of Financial Activities	9

PANS / PANDAS UK

REPORT OF THE TRUSTEES for the Year Ended 5 April 2021

The trustees present their report with the financial statements of the charity for the year ended 5 April 2021. 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 conditions which result in inflammation of the brain, causing a variety of neuro-psychiatric conditions such as OCD, tics and eating disorders.

PANS PANDAS UK (called "we" or "us") is a UK-wide Charity which was established by a dedicated and determined group of parents with children who are affected by PANS or PANDAS. PANS PANDAS UK commenced work as an organisation in 2017 creating a network of doctors and the PANS Physicians Network Meeting, setting up the Facebook support group, website, etc. Charity status was achieved on 22 May 2018.

PANS PANDAS UK was formed in order to raise awareness and understanding of these conditions amongst the general public and medical professionals. It is our mission to ensure that the conditions are known about in every GP Surgery, every school and every hospital, so every child can receive an early diagnosis and effective treatment. We are working closely with a network of doctors in order to ensure better diagnosis and early effective treatment for those suffering with these little-understood, but life-changing conditions.

Please visit our website for more information:

www.panspandasuk.org

FINANCIAL REVIEW

Going concern

The Charity's financial position in the year 2020/21 was, quite fortunately, unaffected by Covid. In the previous year (2019/20), our income from individual donations was £4,808, and this rose to £19,349 in 2020/21. We did not expect individual donations to be affected, but nor did we expect such a significant rise. The income source which may have been susceptible to Covid was fund-raising events. In 2019/20, events raised £17,811, but this too rose substantially to £31,140 in the last financial year of 2020/21. The Charity has survived Covid in a strong position.

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing document

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

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity number

1178484

Principal address

Lowfields
Long Itchington Road
Offchurch
Leamington Spa
CV33 9AY

Trustees

Mrs G Tuckey
Mrs V Burford
P Hall
Ms C Hvid
Ms Z Van Den Bosch

Independent Examiner

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

PANS / PANDAS UK

**REPORT OF THE TRUSTEES
for the Year Ended 5 April 2021**

Approved by order of the board of trustees on 11 June 2021 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 2021.

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

11 June 2021

PANS / PANDAS UK

STATEMENT OF FINANCIAL ACTIVITIES
for the Year Ended 5 April 2021

	Notes	5.4.21 Unrestricted fund £	5.4.20 Total funds £
INCOME AND ENDOWMENTS FROM			
Donations and legacies		50,727	22,751
EXPENDITURE ON			
Raising funds		18,522	16,791
NET INCOME		<u>32,205</u>	<u>5,960</u>
RECONCILIATION OF FUNDS			
Total funds brought forward		22,415	16,455
TOTAL FUNDS CARRIED FORWARD		<u><u>54,620</u></u>	<u><u>22,415</u></u>

PANS / PANDAS UK

BALANCE SHEET
5 April 2021

	Notes	5.4.21 Unrestricted fund £	5.4.20 Total funds £
CURRENT ASSETS			
Cash at bank		54,620	22,415
NET CURRENT ASSETS		54,620	22,415
TOTAL ASSETS LESS CURRENT LIABILITIES		54,620	22,415
NET ASSETS		54,620	22,415
FUNDS	4		
Unrestricted funds		54,620	22,415
TOTAL FUNDS		54,620	22,415

The financial statements were approved by the Board of Trustees and authorised for issue on 11 June 2021 and were signed on its behalf by:

V Burford - Trustee

NOTES TO THE FINANCIAL STATEMENTS
for the Year Ended 5 April 2021

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.

2. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 5 April 2021 nor for the year ended 5 April 2020.

Trustees' expenses

There were no trustees' expenses paid for the year ended 5 April 2021 nor for the year ended 5 April 2020.

3. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

	Unrestricted fund £
INCOME AND ENDOWMENTS FROM	
Donations and legacies	22,751
 EXPENDITURE ON	
Raising funds	16,791
NET INCOME	5,960
 RECONCILIATION OF FUNDS	
Total funds brought forward	16,455
TOTAL FUNDS CARRIED FORWARD	22,415

NOTES TO THE FINANCIAL STATEMENTS - continued
for the Year Ended 5 April 2021

4. MOVEMENT IN FUNDS

	At 6.4.20 £	Net movement in funds £	At 5.4.21 £
Unrestricted funds			
General fund	22,415	32,205	54,620
TOTAL FUNDS	<u>22,415</u>	<u>32,205</u>	<u>54,620</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	50,727	(18,522)	32,205
TOTAL FUNDS	<u>50,727</u>	<u>(18,522)</u>	<u>32,205</u>

Comparatives for movement in funds

	At 6.4.19 £	Net movement in funds £	At 5.4.20 £
Unrestricted funds			
General fund	16,455	5,960	22,415
TOTAL FUNDS	<u>16,455</u>	<u>5,960</u>	<u>22,415</u>

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

	Incoming resources £	Resources expended £	Movement in funds £
Unrestricted funds			
General fund	22,751	(16,791)	5,960
TOTAL FUNDS	<u>22,751</u>	<u>(16,791)</u>	<u>5,960</u>

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

	At 6.4.19 £	Net movement in funds £	At 5.4.21 £
Unrestricted funds			
General fund	16,455	38,165	54,620
TOTAL FUNDS	<u>16,455</u>	<u>38,165</u>	<u>54,620</u>

NOTES TO THE FINANCIAL STATEMENTS - continued
for the Year Ended 5 April 2021

4. MOVEMENT IN FUNDS - continued

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	73,478	(35,313)	38,165
TOTAL FUNDS	<u>73,478</u>	<u>(35,313)</u>	<u>38,165</u>

5. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 5 April 2021.

PANS / PANDAS UK

**DETAILED STATEMENT OF FINANCIAL ACTIVITIES
for the Year Ended 5 April 2021**

	5.4.21 £	5.4.20 £
INCOME AND ENDOWMENTS		
Donations and legacies		
Donations	50,489	22,751
Exhibitor / Awareness	238	-
	50,727	22,751
Total incoming resources	50,727	22,751
 EXPENDITURE		
Other trading activities		
Fund raising	16,959	6,713
Conferences	-	3,865
PANS Physician's network	-	2,317
Exhibitor / Awareness	1,563	3,896
	18,522	16,791
Total resources expended	18,522	16,791
 Net income	32,205	5,960

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 2021

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
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11 June 2021