



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:

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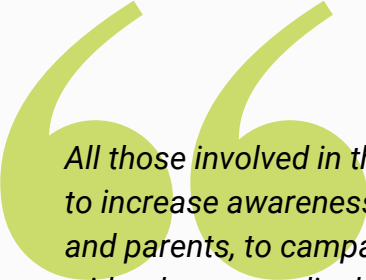
Section 1: What are PANS and PANDAS, and what is PANS PANDAS UK?

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

PANS PANDAS UK (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.

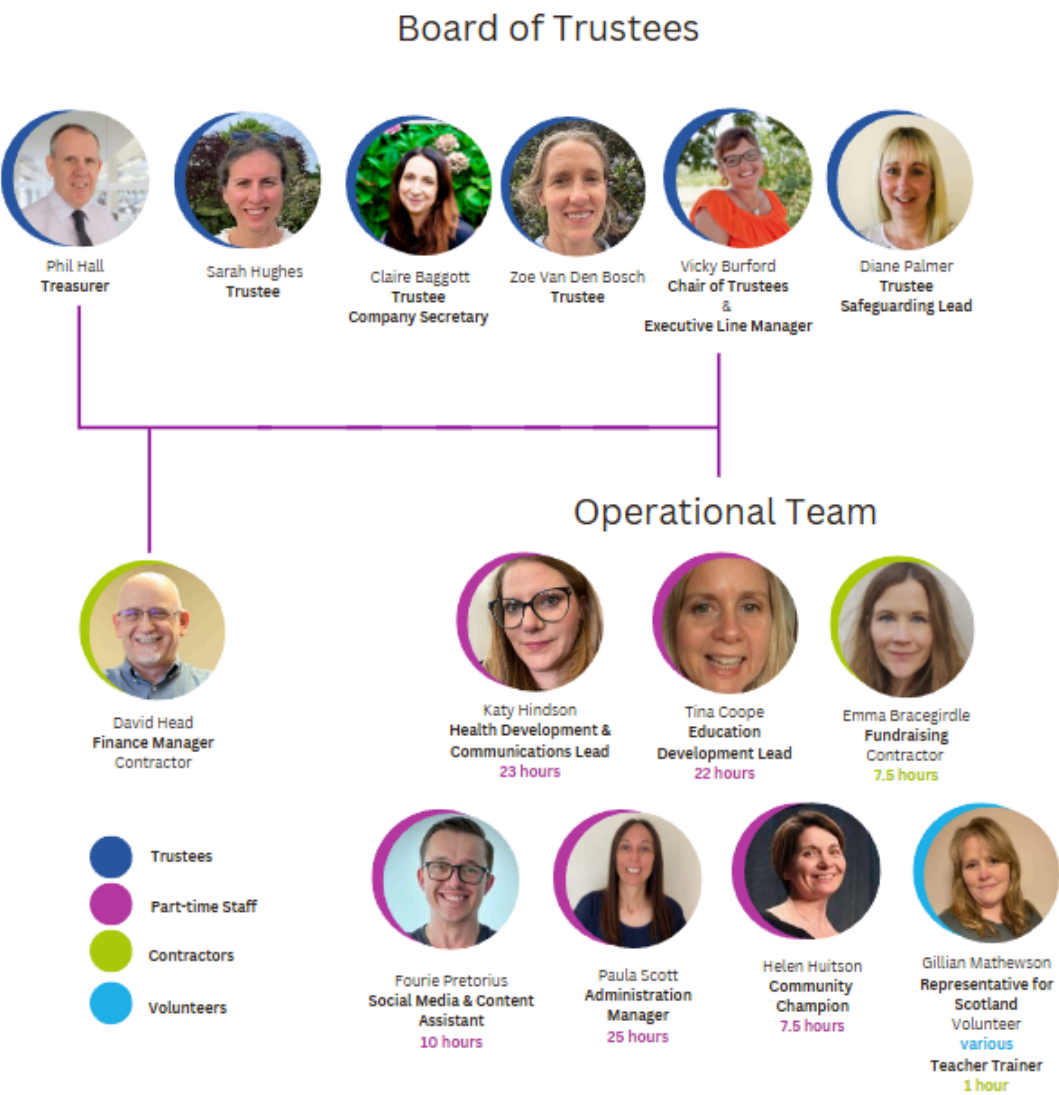
Section 5: Structure, Governance and Management

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

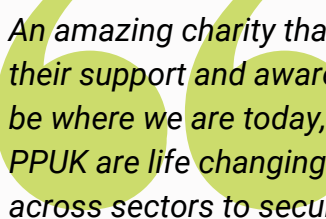
Our community told us that they wish they could get together in person with other families, and our Youth Board reported wishing they could meet other children with PANS or PANDAS in person. We listened and recruited a part time Community Champion to develop a plan to develop and roll out the in-person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

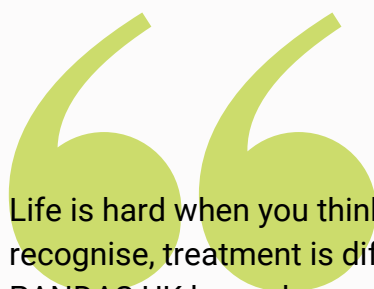
6.2.13 Launched an Annual Fundraising Campaign

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.

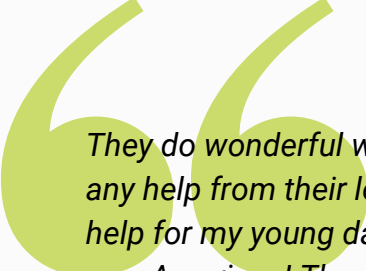
PANS PANDAS UK has worked collaboratively with multiple educational institutions such as:

- 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)

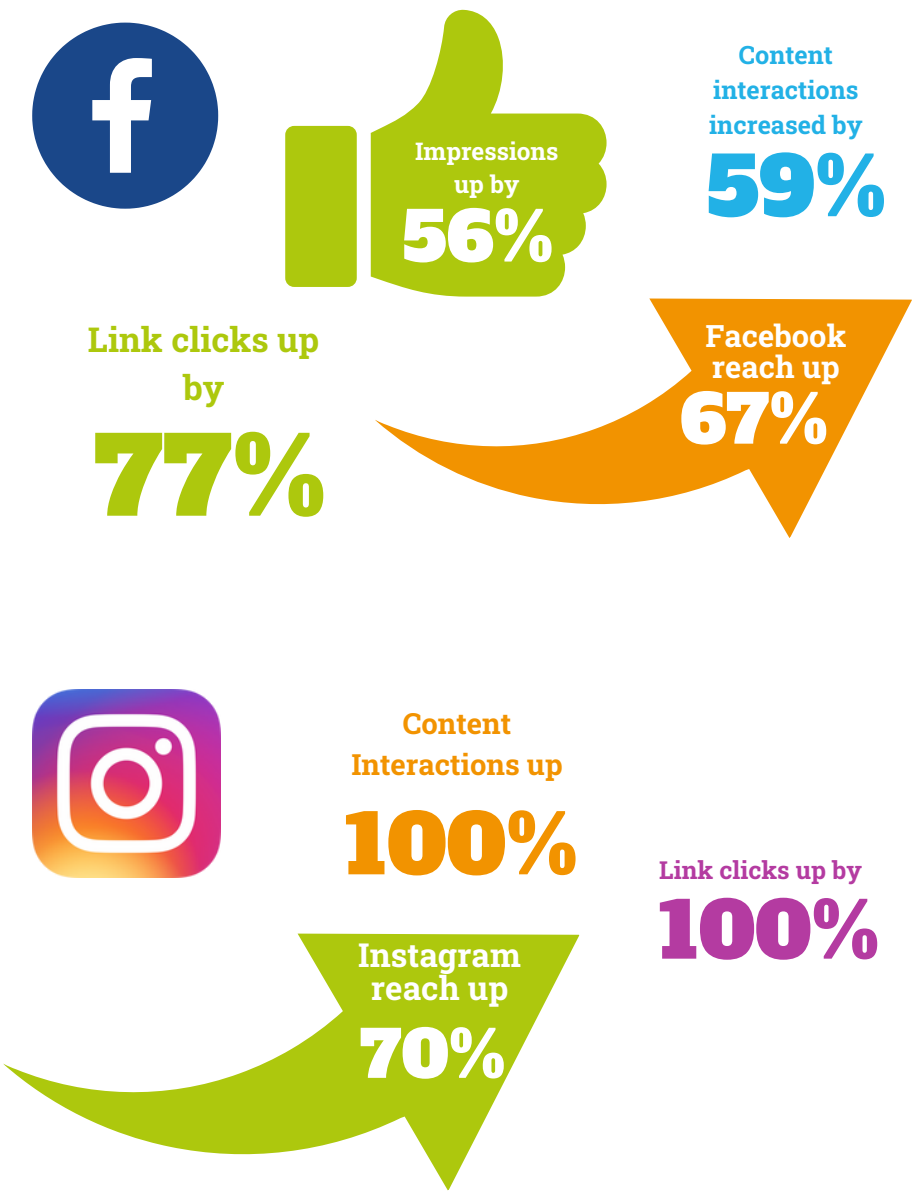
These collaborative strands of work have led to multiple new PANS and PANDAS education resources being published, raised awareness across different sectors of education, provided opportunities to deliver the teacher training over a larger network, the inclusion of PANS and PANDAS in education projects 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.

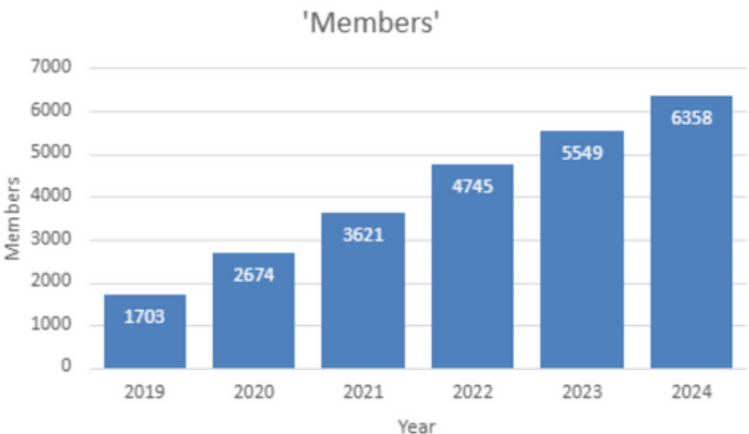
We will provide information and resources to help inform and support families and individuals about diagnosis of PANS and PANDAS, healthcare, managing symptoms and educational support.

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

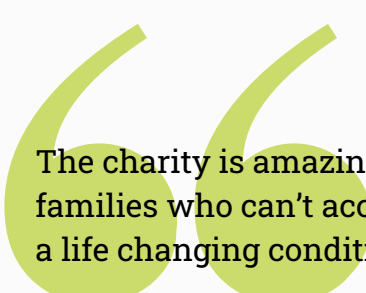
PPUK operates using two bank accounts, as follows:

- 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	77,037	-	77,037	12,968	25,301	38,269

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
	<hr/> 100	<hr/> 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	-
	<hr/> 17,739	<hr/> 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

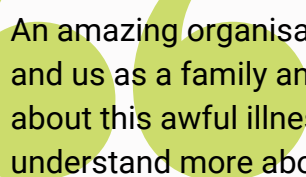
We will attend the NASEN (National Association for Special Educational Needs) Educational Conference in July 2024, present and deliver education workshops at Birmingham Newman University and Manchester Metropolitan University and participate in the Discover Inclusion Online Conference October and attend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

