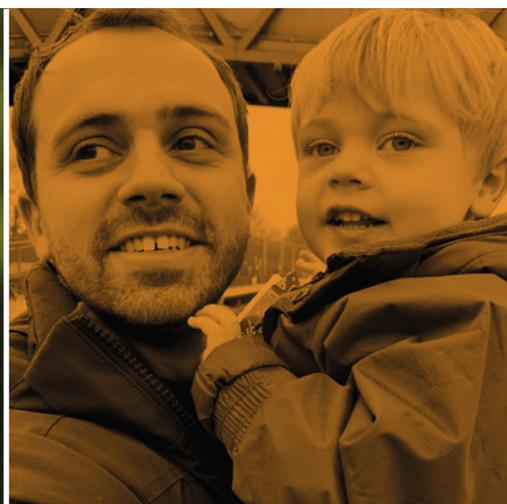




PANS PANDAS UK  
awareness support education

# PANS PANDAS UK NEWSLETTER

ISSUE #2 SPRING 2020



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## Contact Us

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Facebook: PANS PANDAS UK Support Group  
Twitter: @PandasPans  
Instagram: @Pans\_Pandas\_UK



PANS PANDAS UK  
awareness support education



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# WELCOME TO OUR SECOND ANNUAL NEWSLETTER!

**S**o much has happened in the last year, but nothing is in the forefront of our minds more than the Coronavirus Pandemic and the current social distancing measures brought in by the Government in recent days and weeks. These measures have resulted in many people being laid off, businesses closing, the elderly and those with underlying health conditions being isolated, schools closing and exams cancelled.

We all hope of course that the measures will be short-term but for those of us dealing with PANS in our family, there is no short-term measure. The need to avoid allergens, infections and triggers is simply a part of daily life for us.

Many of you will feel that not much has changed in respect of the life of a PANS or PANDAS family, but social distancing and fear of infection is a normal part of our lives and the panic the general public are currently feeling is very much the way many of us feel on a day-to-day

basis. This doesn't however mean that Covid-19 doesn't bring with it concerns for our families and ourselves, along with the added financial burden. We sincerely hope that our Facebook support group, whilst limited, is of some comfort to those of you who are members. We may not be able to meet with you face to face for the foreseeable future, but we are still there on the group with whatever support we can offer.

We were a very new Charity when we published the first edition of our newsletter and now as we approach our second full year as a Registered Charity despite the Coronavirus, we are delighted to share with you our achievements over the last year and our goals for the year ahead.

The support we receive from our loyal members is outstanding and we are proud to represent such a brave, strong and determined group of parents.

There are so many people we'd like to thank, including all the

parents, supporters, organisations, doctors and MP's who have been involved in our work in one way or another over the last year. You know who you are!

Of particular note is the amazing work carried out by our members on a daily basis in our Facebook support groups. Currently sitting at 2,708 members in our main group and 154 in our newer adult PANS group, the members are an incredible resource. From sharing their stories, offering their tips for just getting through the day, as well as lending an ear and offering the most incredible support to others experiencing a particularly difficult time. The amazing courage and determination shown by our members never ceases to amaze us and we thank you for your daily strength, mettle and unfailing humour!

Best wishes  
*The Trustees*  
*PANS PANDAS UK*

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# ABOUT THE CHARITY

**P**ANS PANDAS UK as an organisation was established in the Autumn of 2017 after numerous discussions by a small group of parents with children affected by PANS and PANDAS. Our purpose was twofold. Firstly, we wanted to offer support to the ever-increasing number of parents joining our online support group, many of whom were struggling to obtain a diagnosis and treatment for their children. Secondly, we pledged to seek out doctors who were open to learning about PANS and PANDAS and support them in learning about the conditions.

We decided shortly after establishing PANS PANDAS UK as an organisation however, that we needed to do more and so the charity was formed in May 2018 and this has helped us to raise more funds, open more doors and become much more visible as an organisation.

While we still have a long way to go. Two years ago we weren't aware of even one doctor treating these conditions and awareness was almost non-existent. Now, PANS and PANDAS is becoming far more well known, and whilst it's true that many doctors still (incorrectly) believe a diagnosis is 'controversial' they are at last talking about it!

## OUR CHARITABLE OBJECTIVES 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).'**

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

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# MEET THE TEAM

## TRUSTEES



Georgia Tuckey – Chairperson



Vicky Burford – Secretary



Phil Hall – Treasurer



Cindy Hvid – Adult Lead

The existing Trustees would like to thank Sue Adams who was one of the original Trustees in the formulation of the Charity, and Russell Ritchie who was Trustee for 2019 for their valuable contributions last year. The Trustees would also like to thank Caroline Traa for being one of the original founders of PANS PANDAS UK.

## EXECUTIVE COMMITTEE

**Caroline Traa** – Executive for Scotland

**Natasha Lindsay** – Executive for Northern Ireland (and Chair of NI charity under incorporation)

**Aly Shields** – Executive for Wales

**Sonia Serrano** – Executive Fundraising Administrator

**Toni Whitney** – Executive Media and PR Administrator



Caroline Traa



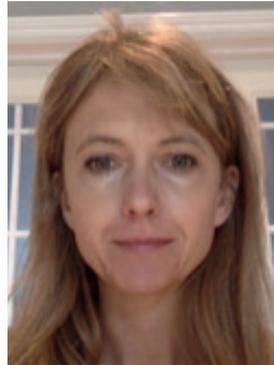
Natasha Lindsay



Aly Shields



Sonia Serrano



Toni Whitney

## FACEBOOK ADMIN TEAM



Johanne Hewlett



Sonia Serrano



Vicky Burford



Cindy Hvid



Aly Shields

# ADULTS WITH PANS

Despite its name, adults can suffer from the neuro-psychiatric symptoms arising from PANS. We have seen a growing number of adults approaching the charity with diagnoses or suspected diagnoses. Despite the age restriction being lifted in 2019 by the National Institute of Mental Health (NIMH), adults are still experiencing much opposition from the medical field and little or no treatment. We are aware of very few doctors who accept that adults can be affected, but the growing number of adults in our Facebook support group and those who contact the charity are testimony to the fact that PANS in adults is very real indeed!

The charity is working hard to identify forward-thinking doctors who are prepared to learn about these conditions in adults and offer treatment. Whilst we have a good number of paediatric doctors on board, we hope to be reporting in our next newsletter that we have a number of doctors who treat adults joining the PANS Physician's Network UK.

## WHEN ADULTS GET PANS MADELINE DYER'S STORY



*"I can't touch that. I can't sit down. This air is dirty. I can't breathe here. There's nowhere I can go. I don't know what to do."*

One day in December 2018, I woke up and I was a different person. That's really how it felt. It was just before my 24th birthday, and I was suddenly terrified of everything. I'd developed severe contamination OCD literally overnight, was hallucinating and paranoid, and I couldn't balance. I just kept falling over.

*"I am possessed. There are too many thoughts in my head — they're crashing into each other, they won't slow down."*

When I went to my GP, I was told it was just anxiety. But a month later, all my symptoms had got even worse. I was now terrified of being on my own, too afraid to

hug anyone, unable to work, and I was crying endlessly. My balance was even more terrible, and I was getting excruciating headaches most of the time. I became convinced that birds and insects were following me, and I couldn't escape them.

*"There are insects crawling on me and birds flying around me. I can feel the beat of the birds' wings in the air near me, the breeze of them against on my skin. I can feel the insects' tiny feet as they crawl over my arms, my legs. But I can't see any insects or birds. Just hear them, feel them."*

A few months after this, I was diagnosed with OCD and sent for therapy ... the therapy did not work.



*“I’m alone. I can’t do this. Everything is too difficult. I can’t escape. What is wrong with me?”*

I was given anti-depressants....  
The anti-depressants did not work.

Five months into this ordeal, I discovered PANS through an OCD support group. A woman told me how her son had been misdiagnosed with OCD when in fact he had PANS. I researched PANS and found that I fitted all the criteria--the only thing that confused me was the ‘paediatric’ part of the name, but then I discovered that the age-limit had actually been lifted. Adults could get PANS too.

Armed with this knowledge, I went back to my GP and asked to be tested for it. I was humoured at first. It was clear the doctors didn’t really believe me. But they ran blood tests and then gave me a trial of the treatment for PANS—antibiotics—to see if it made a difference.

And the most incredible thing happened. Within two hours of starting the first dose of antibiotics, my OCD went away. My sense of balance improved. My headaches disappeared. The hallucinations stopped. I began

hugging people again. I wasn’t afraid. I felt like myself.

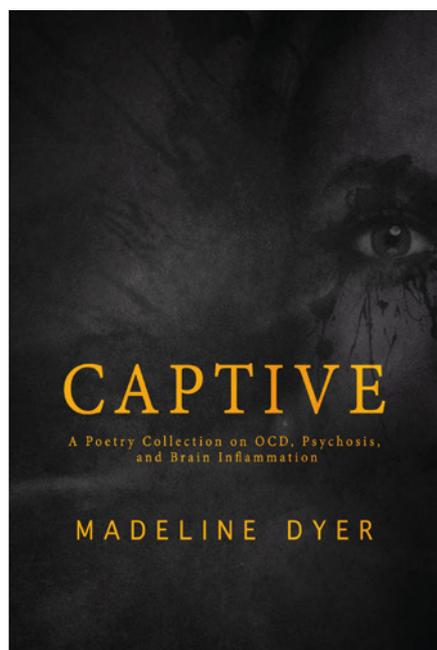
A week later, and I was well enough to work again.

My doctors were amazed and realised that something more than ‘regular OCD’ had been going on all the time. After all, OCD doesn’t respond to antibiotics, but what I had clearly did.

I was promptly referred to an encephalitis expert and given a further thirteen weeks of antibiotics, as well as steroids and anti-inflammatories, while my GP kept telling me that she didn’t understand why the antibiotics were working.

A brain scan revealed several abnormalities and further blood tests indicated autoimmune problems.

I’m currently off the antibiotics as the NHS can only prescribe them for so long. My PANS symptoms have since returned--including the severe OCD and loss of balance--and I am now waiting for a long-term treatment plan to start that will offer a more permanent treatment for my PANS.



Madeline Dyer has written two books about her experiences of PANS as an adult. The first of which, a poetry collection based on the therapy writings she produced while suffering from PANS, is out now. *Captive: A Poetry Collection on OCD, Psychosis, and Brain Inflammation* can be found at Amazon and many other major retailers.

# UK PANS PHYSICIAN'S NETWORK AN UPDATE

GLASGOW  
NEURO-IMMUNOLOGY  
STUDY DAY

## MAKING SENSE OF PANS AND PANDAS

Friday 25th October 2019  
9.30am - 4pm

Lecture Theatre, William  
Quarrier Conference Centre,  
20 St. Kenneth Drive,  
Glasgow, G51 4QD

Consultants £40  
Trainees/AHP's £20

**SELECTED TOPICS:**  
Diagnostic Criteria  
Update on UK Guidelines  
Existing Research  
Investigations and  
Treatments  
Psychiatric Management  
The Adult Viewpoint  
Case Studies  
Supporting a PANS Family

**SPEAKERS:**  
Dr Susan Swedo, MD  
Dr Ming Lim, Neurologist  
Dr Paul Bain, Psychiatrist  
Prof Gareth Morgan (fbc),  
Immunologist  
Dr Tim Ubbi, Paediatrician  
Dr Rory Barr, ST5  
Mr Neil Gilson, Parent  
Mrs Georgia Turkey,  
Chairperson of PANS  
PANDAS UK

Lunch and refreshments will  
be provided. Please email:  
secretary@panspandasuk.org  
with any dietary requirements

To book your place, please go to: [www.panspandasuk.org/events](http://www.panspandasuk.org/events)

Since the inaugural meeting in October 2017, the PPNUK has grown stronger and stronger. There are some incredible doctors who are fighting just as hard as we are for the rights of our children to receive effective diagnosis and treatment. We thank them for their commitment and passion, despite the difficulties many of them face in simply 'believing' in the conditions.

We hold quarterly meetings with doctors in locations all over the country in order to be as accessible as possible to all medical professionals.

The PPN UK meetings are invitation only and aimed at medical professionals, but if you are a medical professional or you know one who wishes to attend, then please ask them to contact us at [secretary@panspandasuk.org](mailto:secretary@panspandasuk.org) for more information and an invitation.

In October 2019 we held the first PANS Physician's Network Training Day in Glasgow which was a great success and we have plans to roll this out to other locations in the UK, including Northern Ireland, Wales, Devon and Cambridge.

These training events are for medical professionals to learn more about PANS and PANDAS, including how to recognise the symptoms, understanding referral requirements, first line testing and basic treatment recommendations.

## COMING SOON – PANS FUNCTIONAL NETWORK UK (PFN UK) MEETINGS

Many of our members prefer to use functional medicine over conventional medicine. PANS PANDAS UK has therefore decided that it would be in the best interests of our members to create a PANS Functional Network (PFN UK) 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. With the current restrictions in place due to Covid-19 the first meeting has been put on hold, but this meeting will resume as soon as it is safe to do so.





# JACK'S STORY

**O**ur son Jack developed tonsillitis as a toddler and became very aggressive overnight. At the time, we put it down to his age, but Jack went on to develop tonsillitis a further 10 times in quick succession and his behaviour proceeded to get worse and worse each time. Not only was he aggressive but had severe

the answers to these changes in behaviour. Tourettes, allergies and normal behaviour were all cited as reasons for his symptoms but this didn't ring true and we were heartbroken and desperate for answers. Not only was Jack suffering mentally, he also became very poorly physically. He lost fingernails and toenails and had very little energy. We had listened to so many different opinions and had been made to feel like we were being paranoid, that we eventually accepted that he would be officially diagnosed with Autism and the

From this moment on, our family's lives changed for the better. Jack was diagnosed with PANDAS and treated with simple antibiotics. Within two weeks we had our son back, the change was unbelievable. The worried look in his eyes was no longer there. His tic had completely gone and his behaviour had drastically improved. He was back to eating normally and was able to leave the house without any anxiety. Jack was diagnosed with having PANDAS (Paediatric autoimmune neuropsychiatric disorder associated with Streptococcal infections). It was also recommended to us that we have Jack's tonsils removed in order to limit the constant strep A infection he was contracting.

Jack had his operation on 1st February 2019, it was a success. Jack continues to be well and despite still showing some mild symptoms of PANDAS we are managing well with the help of our amazing doctor.

There is absolutely no question that 'This Morning' and the parents who were brave enough to go on the show and share their story, have saved our son's quality of life, we are so grateful to them and to 'This Morning' for this.

Neil and Lucie Gilson,  
parents of Jack

*"Some days when he was in this state you would look at him and it was like there was no-one there."*

OCD and a tic which impacted on his friendships. He then developed anxiety, attachment issues and difficulties around communicating and eating. Some days Jack didn't want to leave the house and often wouldn't speak a word. He would bite his own arm as he was so anxious, and we would struggle to get him dressed each day as he said the clothes hurt his body.

We took Jack to many different doctors and we could not find

behavioural characteristics were just something we would have to learn to live with. We felt so alone, and we were so worried for Jack's future.

It was then we saw the feature on 'This Morning'. The segment was called "Did household mould turn our son evil?" and there was a mother talking about her son. I watched it and just felt like I was watching Jack. The symptoms were very similar to our son after he had a strep infection.

# APPG - MARCH 2020



On 3rd March 2020, PANS PANDAS UK met MP's and Peers of all parties, parent representatives and a respected PPN Doctor in parliament in order to begin the APPG process.

## **Main Committee:**

Chair – Ruth Cadbury MP  
Vice-Chair – Munira Wilson MP  
Vice-Chair – Robin Millar MP  
Officer – Baroness Boycott  
Officer – Lord Dubs

## **Other members:**

Caroline Nokes MP  
Mark Pawsey MP  
Julian Lewis MP  
Holly Mumby-Cross MP  
Lord Addington  
Professor Rajat Gupta – Paediatric Neurologist  
Georgia Tuckey – PANS PANDAS UK Chairperson  
Sarah Williams – Parent Representative

Kristina Gray – Parent Representative  
Toni Whitney – Parent  
Rahul Mathur - Parent  
Lucy McDonald, Parent  
Ben Whitney – Parent  
Simon Williams - Parent  
Dr Roswitha Dharampal - Psychiatrist  
Richard Austin  
Sadie Quinn – Administrative Assistant to the Secretary



## Our APPG 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.'*

## A brief summary of the meeting

The Chair, Ruth Cadbury, opened the meeting and progressed through the formal mandate to establish roles and responsibilities for the purposes of the PANS PANDAS APPG.

Georgia Tuckey then delivered the charity's presentation providing an overview on symptom presentation of PANS/PANDAS which included consented, live examples. Treatments were discussed as well as the obstacles identifying access to diagnosis and treatment.

Professor Raj Gupta followed with information from a specialist's perspective on some of the difficulties encountered by both parents and specialists alike in the route to accessing treatment for PANS/PANDAS.

Parent representative, Kristina Gray went on to present the story of her daughter who is currently suffering with PANS, highlighting how the condition has broken down her daughter's happy personality. Kristina emphasised that, despite the fact that she managed to receive private healthcare, this service is not available to all parents and that treatment for this disease should be provided for all of the children who are suffering.

Parent representative, Sarah Williams continued, highlighting her family's problem with living in Cornwall, which is over three-hundred miles from the closest specialist, emphasising the need for a network of specialists throughout the country. A lengthy discussion followed.

## The outcome of the meeting identified the following 'next steps'.

- MPs to 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 NHSE, NHSS, NHSW, NHSE, HEE.

*We still have a long way to go and of course with the recent Coronavirus crisis upon us, progress will inevitably be delayed, but in spite of this we ask you all to please continue to contact your MP's. There is power in numbers and a template letter is available on our website. The more MP's that we can involve, the stronger our case will be.*

# PARENT SURVEY 2020

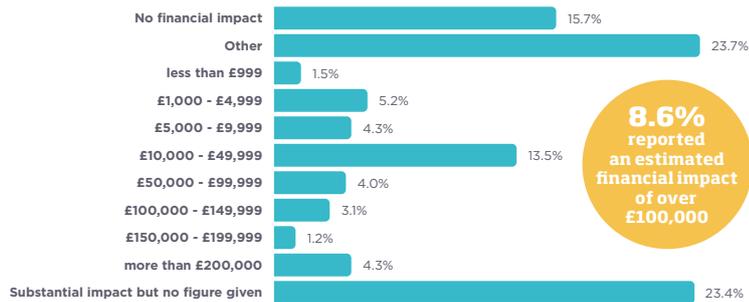
In 2018 we undertook a survey of parents on our Facebook group which gave us some indication of the financial, emotional and physical burden that having a child with PANS or PANDAS can inflict upon a family. In addition to this, questions relating to diagnosis, experiences with doctors, schools and workplaces were asked and it has to be said, the results were shocking!

With the substantial growth of our Facebook support group we felt that it would be prudent to re-do the survey with a larger cohort. Perhaps unsurprisingly the results of our 2020 survey almost mirrored that of the original one, with just a few small improvements being seen. We are hopeful that this is due to the awareness raising which has taken place over the last year, but we cannot be sure. The results can be seen in the visuals below:

## PANS PANDAS UK 2020 Parents Survey

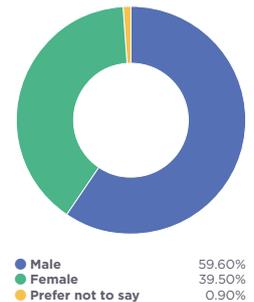


### Financial impact

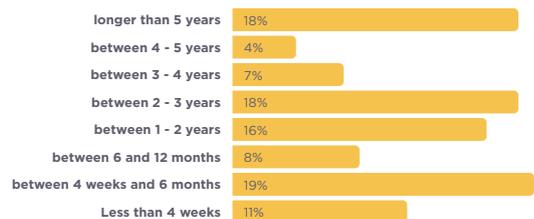


**35%** say their child has missed more than 6 months of school due to their symptoms.

### Gender of child



### How long after onset of symptoms did it take to get a diagnosis of PANS, PANDAS or Immune Mediated Behavioural Diagnosis?

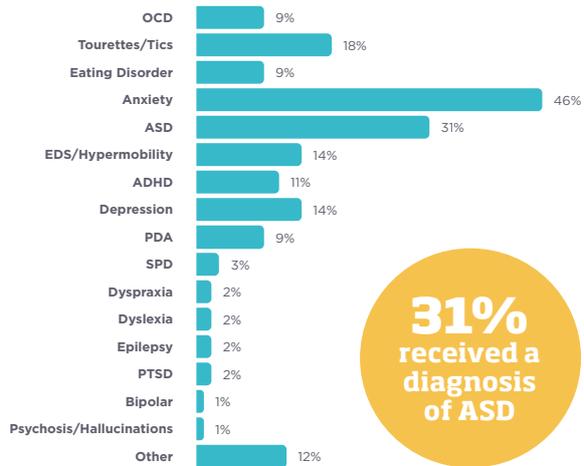
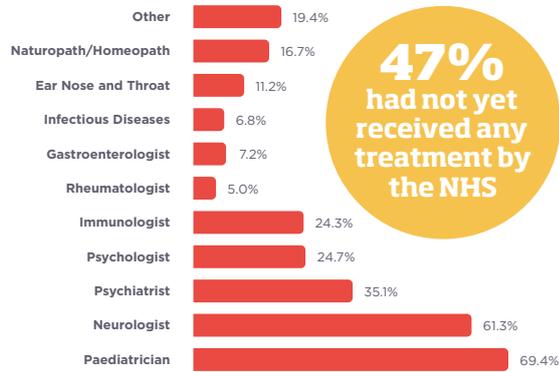


### Have you had to leave employment because of PANS or PANDAS?

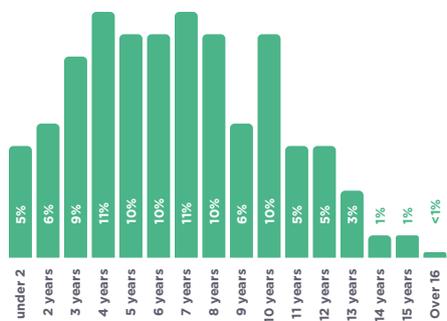


**19%** of parents say their paediatrician was aware of the conditions but considered it a 'controversial' diagnosis.

**Which specialists did you see to get a diagnosis of PANS/PANDAS or suspected PANS/PANDAS?**



**Age at onset of symptoms**



31% of respondents have been reported for concerns regarding their parenting and or/referred to parenting classes.

**1%** had their child removed by social services

**11%** have had to travel abroad for treatment

**37%** have had to seek private treatment

**95%** say GP did not suggest PANS or PANDAS

# PANS, PANDAS AND AE CONSUMER SURVEY

**T**REND Community is an organisation who use online algorithms to identify data shared within social networks in order to try to capture real-life patient experiences. This data is anonymized, analysed and summarized into a customised Community Voice Report.

The PANS, PANDAS and AE report discusses issues such as disease burden, disease management and goes on to analyse some of the more significant terms discussed within the group. Finally, the report advises on areas where further investigation may be required.

*“One of the biggest frustrations among participants is that symptoms of these diseases are often mistaken as psychiatric rather than bacterial or viral. When doctors see signs of OCD, they don’t necessarily know to check for an underlying problem.” (PANS, PANDAS and AE, TREND Report, p8)*

This report for PANS, PANDAS and AE was published in February 2020. The full report can be downloaded from our website.

**PANS, PANDAS, AE Community Voice Report**  
VOLUME 1, ISSUE 1 - JANUARY 2020

**How It Works**

**Data Exploration and Health Initiatives**

*“I wish specialists understood how horrible this condition is, for everyone involved, but especially the child. This is a trauma that the child will carry on for the rest of their lives regardless of them getting better or not.”*

## PANDAS/PANS NI

Forging a future through  
Awareness & Co-operation



# NORTHERN IRISH CHARITY

**L**ong before PANS PANDAS UK was even thought of, Natasha Lindsay, a PANDAS mum from Northern Ireland had already made headway in raising awareness with a Channel 5 documentary 'Medical Mysteries' screened in March 2016 and an appearance on This Morning in September 2016.

Natasha has been on the NI Charity Commission's 'Registration of Interest' list to set up a PANDAS charity since June 2017 but was warned that the waiting list was a very long one. Almost 3 years later, we are

delighted to hear that Natasha has finally been able to formally submit her application and so it shouldn't be too long now before the official PANDAS/PANS NI charity is up and running.

*"We are currently waiting on our official Northern Ireland Charity registration number and all submissions have been made. Once we obtain this it will enable us to really start making a difference to the local families we support through fundraising and awareness programmes. There is a real need for practical support*

*among our local families, and for education and knowledge boosting for those medical professionals involved in supporting them. I am passionate, that as a charity, we make a difference for those just embarking on this journey."*

Natasha Lindsay  
PANDAS/PANS NI Charity

We are thrilled that this is finally happening after all Natasha's hard work and patience. We look forward to working with her and supporting the Northern Irish Charity in any way we can.

## CAMERON'S HAVEN



**H**aving experienced first-hand how these conditions can devastate families, Natasha and her husband Jonathan have generously opened up their holiday cottage in Islandmagee for cost free breaks to families from the UK and Ireland with children suffering with acquired brain injury, Encephalitis, PANS or PANDAS.

Islandmagee is a peninsula located at the foot of the Antrim Glens on the spectacular North Coast of Northern Ireland. This beach cottage hideaway is situated in the tranquil surroundings of Ferris Bay.

The healing powers of water are evident within minutes of your arrival and sitting on the porch listening to the gentle lapping of the waves is relaxing and cathartic.

Obviously with the Coronavirus crisis, travelling is limited and some bookings have had to be rescheduled, but more information can be found at [www.camerons-haven.weebly.com](http://www.camerons-haven.weebly.com) and if you would like to register your interest in booking some time at Cameron's Haven later in the year, then please fill in the online form and Natasha will get in touch with you.

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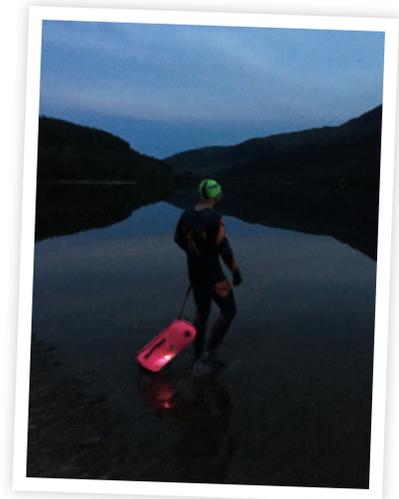
# FUNDRAISING

## Notable Fundraisers in 2019

**We could not do our work without the incredible support from all the people who fundraise for us. We are extremely grateful to everyone who has donated or hosted an event, attempted a challenge however large or small.**

**Neil Gilson** undertook the 24 hour swim challenge and raised an incredible £6,273.25 for PANS PANDAS UK.

Neil braved the waters of Loch Lubnaig in Scotland to raise money and awareness due to his son developing PANDAS. You can read about his son Jack's journey later in this newsletter. Neil swam one mile per hour over the course of 24 hours in a freezing loch, taking whatever time was left after completing each mile to rest before entering the freezing water again to swim the next mile. Neil did this through the night, in the pitch dark and did not let up, we have live video evidence to prove it! What an amazing challenge, what an amazing man! Thank you Neil, we salute you!



**Neil braved the waters of Loch Lubnaig in Scotland to raise money and awareness due to his son developing PANDAS.”**



## Isle of Wight Fundraiser

During 2019, Tina Thomas from the Isle of Wight, organized a variety of fundraisers including a couple of quiz nights at her local pub the Castle Inn and a madcap Boxing Day Swim which raised a combined total of £1,800.

Huge thanks to Tina, to everyone at the pub and to the crazy bunch who dared to take a dip in the freezing waters off the Isle of Wight in the middle of winter!



**BIRTHDAYS**

ON FACEBOOK

*Facebook Birthday Fundraisers*  
An incredible £8,432 has been raised over the course of the year thanks to all the wonderful Facebook Birthday Fundraisers which have taken place during 2019. Thank to everyone who was kind enough to give up their birthday presents in exchange for a donation to PANS PANDAS UK.



**Donna Shore** trekked to the top of Snowdon and raised an amazing £2,537.50 for PANS PANDAS UK.

Despite suffering from several autoimmune disorders which only made her ascent even more challenging, Donna decided that this would be a good way to highlight the daily struggles faced by her young daughter who has the double diagnosis of both PANDAS and PANS. This determination is not uncommon amongst parents of children with these conditions, but Donna really pushed herself out of her comfort zone and we couldn't be more grateful. Thank you Donna, you truly are incredible!

## Match Funding

Many larger employers match fund their employees fundraising activities and so if you are planning to do some fundraising for us, please check with your employer before you start as you may be surprised what they can offer.

## Money for Nothing!

*Amazon Smile*, *easyfundraising*, *Give while you live* and *The Giving Machine* are all online platforms which allow you to raise money while you shop for your everyday items. Every time you make a purchase via these platforms a donation is made to PANS PANDAS UK at no cost to you.



## Fundraising Packs

These are currently being prepared and will soon be available to order from our website. With lots of advice for organising your fundraising event and fun ways to raise money, it's a great move.

## Fundraising Platforms

We are so sorry to hear that the very first fundraising platform we signed up for 'Wonderful.org' is no longer active and we thank them for their help in setting us up on our fundraising journey while we were still a young charity.



## Set up a standing order

Please consider donating a regular amount to our account. This allows us to budget more accurately and make plans ahead of time.  
Bank Details here:  
Bank: Santander  
Account Name: PANS PANDAS UK  
Account Number: 23328323  
Sort Code: 09-01-29

WARRIORS

# PANS AWARENESS DAY - 9TH OCTOBER 2019

Last year one of our valued members Aly Shields wrote and recorded a song for the charity to release on PANS Awareness Day. This beautiful and moving song has been viewed more than 6.5k times and shared relentlessly on social media. Thanks go to 'A Gent Orange' who featured in the song along with the wonderful children's choir PhilHarmonics. The song is available on our YouTube Channel PANS PANDAS UK and you can download your own copy for 99p from iTunes and Google Play.

The video was put together by Mike Shields Photography, and every child featured in the photographs is a child who is suffering with PANS or PANDAS. This song really highlights the terrifying nature of these conditions and we are grateful to Aly for her poignant words.





*"This wasn't a hard song for me to write. Every sentence has been scratched into my heart over the many years of our PANS PANDAS journey. 'A Gent Orange' who works with children in our community using expression through rap, delivered his part with genuine passion after listening to our experiences. PhilsHarmonics took on a most special role too, by becoming the voices of our children who are too ill to sing, and with the last verse sung by Seren, I challenge anyone with any compassion not to be moved. During my involvement with the charity I have shared in other families' painful experiences; their children ignored by health professionals; their fight for acknowledgement and treatment, their sheer tenacity to be heard. I am proud to be part of the PANS PANDAS UK army of families and that is what gave me the refrain 'We are the Warriors'"*





# REGIONAL SUPPORT MEETINGS

**T**he regional support meetings have been very successful and provide members with the opportunity to meet face-to-face. Usually these take place in a hotel lounge or similar location and are relaxed and informal occasions allowing people to meet with others in a similar situation. Sometimes it's only someone who has walked in your shoes who can truly understand what you are experiencing.

Currently we have support meeting which normally take place in the following locations:

**Guildford** – Kathryn Gillett

**Liverpool** – Clare Marie

**London** – Kathryn Gillett

**Northern Ireland** – Natasha Lindsay

**North Lincolnshire** – Jane Bird

**North Wales** – Aly Shields

**Scotland** (various locations) – Caroline Traa

**Warwickshire** – Vicky Burford

**Winchester** – Helen Pemble

Obviously, with the Coronavirus social isolation measures currently in place, we will not be holding any of these meetings for the foreseeable future, but keep an eye on our website and the events section on our facebook support group and as soon as these support events are back up and running we will let you know.

For more information please email [secretary@panspandasuk.org](mailto:secretary@panspandasuk.org)

# ANNUAL GENERAL MEETING 2019

**T**he AGM was held at the Waterloo Action Centre, 14 Baylis Road, London on a very warm sunny day in June 2019.

The Trustees of the charity were joined by 18 individuals from all over the country, some from as far afield as the Isle of Wight and Liverpool. The trustees were humbled by the efforts so many made to be there.

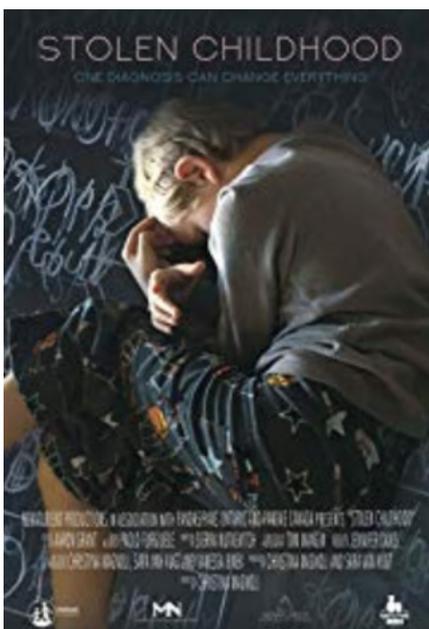
At the start of the meeting the powerful documentary 'Stolen Childhood' was screened and then lunch was served to enable everyone to absorb the contents of the documentary and allow members time to get to know each other a little before the meeting began.

In brief, we undertook a review of the year, reported on the PANS Physician's Network and outlined fundraising efforts for the previous year. Then we heard from the Treasurer who confirmed that the charities finances were in order. We then outlined the charities plans for 2020 and beyond. Following this a call was put out for volunteers and then a lengthy discussion took place with a number of actions suggested for the charity going forward.

Minutes for the AGM can be obtained by emailing [secretary@panspandasuk.org](mailto:secretary@panspandasuk.org).

Thanks to Novaturient Productions for granting permission to allow PANS PANDAS UK to screen the first public viewing of 'Stolen Childhood' in the UK. It was well received.

Due to the Coronavirus crisis and the resulting social distancing measures implemented, Novaturient Productions have kindly released Stolen Childhood to be viewed for free and this can be seen on our website.



## PLANS FOR 2020/2021

- Continuation of APPG
- Meetings with NHS England, NHS Wales, NHS Scotland
- Approval by Royal Colleges of the UK Treatment Guidelines
- More training days for Medical Professionals
- Online training modules for Teaching Staff
- Online training modules for GP's
- Continue to work on the proposed TV Documentary
- FAQ's video for website
- Awareness videos
- Case Study Leaflets

# The sky is the limit!

With the incredible support of so many of you we have been able to achieve an enormous amount in 2019 and have even greater plans for 2020 and beyond. We hope that this newsletter gives you some insight into how PANS PANDAS UK is working towards a better future for our children and if you feel inspired to contribute to our work then we welcome all donations. See our website for details of how to donate.



**PANS PANDAS UK**  
awareness support education

## **PANS** Diagnostic Criteria – at a glance

**PANS** is a medical condition which is triggered by a misdirected immune response causing inflammation in the brain, leading to both physical and psychiatric symptoms. Despite its name, **PANS can affect any individual at any age.**

PANS is a clinical diagnosis and a diagnosis of exclusion. There is currently no specific test which will prove or disprove the condition and a diagnosis is to be made based on the analysis of the patient's medical history, a review of their current symptoms and a physical examination.

Lab work and additional testing can be ordered to identify an infectious trigger, rule out other diagnoses and inform treatment plans.

**In order for a diagnosis to be made, presentation of the following symptoms must occur:**

**An abrupt, acute onset (usually within 24 hours) of Obsessive Compulsive Disorder (OCD) or severely restricted food intake along with two or more of the co-morbid symptoms listed here:**

- **Anxiety (heightened anxiety, separation anxiety, irrational fears, panic episodes)**
- **Emotional Lability and/or Depression**
- **Irritability, Aggression, and/or Severely Oppositional Behaviours**
- **Behavioural (Developmental) Regression**
- **Deterioration in School Performance**
- **Motor or Sensory Abnormalities (tics)**
- **Insomnia and/or Sleep disturbances**
- **Enuresis and/or Urinary frequency**

Whilst not part of the diagnostic criteria, Psychosis and/or Hallucinations have been reported in 25% of cases

## **PANDAS** Diagnostic Criteria – at a glance

**PANDAS** is a subset of PANS. Similarly, it is a neuropsychiatric condition which is triggered by a misdirected immune response to a Group A Streptococcal (GAS) Infection which can occur in many parts of the body, not just the throat and results in an inflammation of a child's brain.

Symptoms can appear whilst the infection is still present or several months later. As with PANS it is a clinical diagnosis.

PANDAS symptoms can then appear to wax and wane with the child experiencing flares periodically, following illness or periods of stress.

**The child is usually between the ages of 3 and puberty when first symptoms occur,** and they usually appear following a streptococcal infection such as Sinusitis, Ear infections or Scarlet fever.

In some cases, children can carry the streptococcus bacteria without showing any signs of illness.

**In order for a diagnosis to be made, presentation of the following symptoms must occur:**

**An abrupt acute onset of Obsessive Compulsive Disorder (OCD) and/or tics (particularly multiple, complex or unusual tics)**

**In addition to OCD and/or tics, children can also experience a range of symptoms including all of the co-morbid symptoms listed for PANS as well as food restrictions.**

If you would like more information on both conditions, please refer to the 'Information and leaflets' section on our website.

## THANK YOU TO OUR MANY CORPORATE SUPPORTERS

