

UK Paruresis Trust Annual Report 2023/24

The organisation was formed in 2002, initially as a charitable association (UKPA), becoming a charitable trust (UKPT) in 2005. We currently have five trustees, all of whom have first-hand experience of paruresis and have attended UKPT weekend workshops. Our trustees have a variety of experience and expertise, which they are able to bring to the UKPT – organisational, financial, psychological and charitable – in addition to the essential qualities of compassion and empathy needed to help people affected by this difficult condition.

Our trustees are:

Chairman:

Andrew Smith (M.A. Cantab)

Treasurer:

David Winton

Committee Members:

Ann Allcoat LRAM GRSM

Peter Daw BSc MSc Clin.Psychol.

Dr Ian Harris PhD

(Jonathan Jones resigned April 2023)

Honorary Advisors:

Peter Daw BSc MSc Clin. Psychol.

Matt Lane MB ChB BSc MA

James O'Neill Psychotherapist and Psychoanalyst

Jonathan Jones (from April 2023)

Another year has come to an end giving us the opportunity to look back and reflect on the work of the UK Paruresis Trust throughout 2023/24.

We continue to be inspired by people's determination to beat paruresis. Every workshop brings more people ready to do whatever it takes to reclaim their lives from the restrictions that paruresis inflicts.

In the wake of covid we see people emerging from home-based seclusion, who want to travel again and make up for lost time. The ability to use plane toilets has always figured high in people's motivation to beat paruresis, but as the pent-up desire to travel the world has surfaced, it's become even more of an issue. Flying with paruresis is possible, as several of our globe-trotting trustees can confirm. So can this workshop attendee, who says:

“We have just returned from Australia, a trip involving five flights all long enough to need to urinate at least once.

The two workshops you ran utterly transformed my flying experience they had a massive effect.

I cannot thank you enough.”

It's so good to receive comments such as this. Sometimes charity trustees can get bogged down in the quest for funding, data protection issues, health and safety, technology challenges etc. Then we're suddenly reminded of the difference we can make, and it's all worthwhile.

Trustees and Volunteers

All trustees and workshop leader volunteers have experienced paruresis and have attended past workshops themselves. Some additional volunteers are aware of paruresis through the experiences of family or friends.

We now have volunteers who help out with financial reporting, fundraising, search engine optimisation on the website, proofreading, and campaigns reaching out to other organisations and companies. All contributions are much appreciated.

Regular trustee meetings happen online due to our geographical spread. However we meet in person once a year to discuss the work of the organisation face to face and in depth.

The contribution of trustees and volunteers is extremely valuable to the charity. This enables us to describe the organisation as being truly user-led, with services shaped around the identified needs of people who have lived experience of paruresis.

Jonathan Jones stepped down from the Trustee board in April 2023 due to pressure of work. We were delighted that he agreed to continue his involvement with UKPT by becoming an Honorary Advisor. We are indebted to all our honorary advisors who give their expertise as required.

Website

Throughout the year, we continued to have well over 1000 people visiting the website each month.

The website continues to require regular attention to ensure a flow of new information, make new links and respond to feedback.

We are indebted to our website design company Light Bulb Web Design Ltd. for their sensitive support with our website needs.

The internet is still the way in which more than 89% of people with paruresis find us and find out about paruresis. Signposting to our website from health professionals only happens for around 4% of website visitors. We hope that our awareness raising activities throughout 2024/25 may help to increase that figure.

In March 2023 we once again reached the required standard to be awarded the Patient Information Forum Quality Mark for Health Information - the PIF Tick. This quality mark demonstrates our commitment to ensuring that the information we give out on our website, in our blogs and in our leaflets is accurate, reliable, and hopefully fairly easy to understand. As a result of this, GPs and other Health professionals can now give information about UK Paruresis Trust in the form of an "Information Prescription" to anyone presenting with the symptoms of paruresis.

Media

We continue to post regular social media activity on Facebook, YouTube, X (formerly known as Twitter), and Instagram. They all feature items of interest to people who experience paruresis, and raise awareness of its existence. We published 13 blogs during the year, which feature a variety of topics, such as urine testing, school toilets and how UKPT manages reviews and feedback. These blogs were read in excess of 8,000 times.

Finance

We are extremely grateful to our regular donors, many of whom have attended UKPT workshops and have first hand experience of paruresis themselves.

In January 2023 we were awarded two year funding from the National Lottery Community Fund for our "Breaking Free From Paruresis" project. Essentially this will fund our awareness raising activities – an extremely important aspect of our work.

Our income for the year 2023/24 was £42,440.

Our expenditure was £25,093.

Workshops

We ran 2 online workshops with 12 attendees.

We ran 3 hotel-based beginners' workshops throughout the year, with 29 attendees.

We ran 4 hotel-based follow-up workshops throughout the year, with 31 attendees.

We received this feedback from women who attended a follow up workshop:

"I've actually been making a lot of progress recently and managed to go easily in situations I hadn't been able to wee in for ... like 10 years."

"I'm really working on reducing my safety behaviours - the workshop really did help tremendously."

"I think the follow up workshop was one of the best experiences of my life, would recommend it to anyone any time."

"I would say the same - the follow-up workshop was such a good experience and I would recommend anyone to do it."

Online Support Groups

Separate online (zoom) support groups for men and women continue to fill a need. Attendees can compare experiences and share strategies which have been useful for them. It gives them an opportunity to feel less isolated in the knowledge that other individuals are facing similar difficulties in their lives.

Some post-workshop WhatsApp groups are popping up amongst groups of people who bonded particularly well during their UKPT weekend workshop. Those who live near each other can act as pee-buddies to practice desensing.

Individual support

Some individuals with paruresis need one-to-one support when they are perhaps unable to attend a workshop for a variety of reasons. Some may have particular needs that are best met by individual support. Trustees are able to offer online or telephone support to individuals in those circumstances.

Governance

The trustees place the highest importance on having essential and appropriate governance structures in place. This includes a commitment to ongoing reviews of all policies and procedures. A biennial audit of policies and procedures was carried out over the winter of 2023/24 to ensure everything we state we will do, is carried out.

We are registered with the Fundraising Regulator to demonstrate our commitment to fundraising best practice, through meeting their Code of Fundraising Practice.

Administration

We are grateful to our Administrative Contractor who has willingly taken on everything we have asked of him - contributing to the work involved in the PIF Tick, day to day maintenance of the website, expanding our social media presence, administering our workshops and keeping our various administrative processes in order.

2024/25

The news of the successful lottery application at the very end of 2023/24 gave finances, and trustees, a welcome boost. We look forward to reaching more people who experience paruresis and helping them to learn how Cognitive Behaviour Therapy techniques can help them to overcome this distressing and life affecting condition.

Andrew Smith

Chair

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