

UK Paruresis Trust Annual Report 2022/23

The organisation was formed in 2002, initially as a charitable association (UKPA), becoming a charitable trust (UKPT) in 2005. We currently have six 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

Honorary Advisors:

Peter Daw BSc MSc Clin. Psychol.

Matt Lane MB ChB BSc MA

James O'Neill Psychotherapist and Psychoanalyst

As the UK emerged tentatively from covid restrictions at the beginning of the year, the UKPT equally tentatively returned to running hotel based weekend workshops in addition to online workshops, which continue to be part of our regular offer.

Even now, a year later, some workshop attendees still tell us that the effects of lockdown continue to affect their lives. It has been harder for some people with paruresis to free themselves from the social restrictions that we all experienced during the covid outbreak. Being unable to go out and experience different toilets in different places has meant that some people have struggled to maintain positive paruresis-beating habits. The UKPT continues to learn from the people with whom we come into contact, and to help them find ways of moving forward in their paruresis journey.

Trustees and Volunteers

All trustees and workshop leader volunteers have lived experience of paruresis and have attended past workshops themselves. Some additional volunteers are aware of paruresis through family members' or friends' experiences.

We now have volunteers who help out with financial reporting, fundraising, marketing, search engine optimisation on the website, and proofreading. All contributions are much appreciated.

Trustees and workshop leader volunteers generally meet annually to give their views on current and future developments in the organisation, and to undergo any training which has been identified as needing to be carried out. In 2020 and 2021 this was not possible due to covid restrictions. Regular trustee meetings continued via zoom during this time, but it was good to be able to meet in person again towards the end of 2022.

The contribution of trustees and volunteers is extremely valuable to the charity, enabling 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.

We are indebted to our honorary advisors who give their expertise as required.

Website

Throughout the year, we had 17,000 + visitors to the website, giving us in excess of almost 54,300 page views.

Welcome funding from the National Lottery Community Fund enabled us to carry out a substantial review of the website. We consulted all of our volunteers, users of our services and as many of our stakeholders as possible. It was encouraging to hear the positive comments that many people made about the website...

It is comforting and helpful to find others who have the same experience. I have learnt some strategies and made me feel I was not so unusual.

Very clearly set out. Loads quickly. Not too "busy" with lots of colours or fonts. Gives plenty of 'where to go now' suggestions.

I realised that others had this problem and I was interested in reading of their experiences and how they coped when in work, travelling and when socialising.

When I first found your website I knew nothing about paruresis I just knew I had issues with going to the toilet so it was a real eye opener and a life saver. I'd lived thinking I was the only person in the world with a condition where I couldn't use a public toilet. The information was very helpful.

The website is well laid out and contains lots of useful information.

I found the information on the website very helpful and this persuaded me to attend.

Gained answers that were unavailable elsewhere.

Loads of great information, pretty decent website in terms of user experience.

Inevitably a few areas arose for improvement. We have a new slimmed down Homepage, developed a new area for resources, which makes all our leaflets easily accessible and downloadable. We have streamlined our workshop with a booking process especially for women, and have given blogs a greater prominence following the positive feedback we received for them. This work took until early 2023 to complete, but our commitment to the

website is such that it will never be “complete” and will always be “work in progress”, as we respond to the changing support and information needs of our users. We are indebted to our website design company Light Bulb Web Design Ltd for their sensitive support with our website needs.

The website review also confirmed that the internet is still the means by which more than 89% of people with paruresis find us and find out about paruresis. Signposting to our website from health professionals only happened for around 4% of website visitors. We are committed to raising awareness of paruresis within the health sector, but it remains a challenge.

At last year’s end, we awaited the outcome of our assessment to see if we had reached the required standard to be awarded the Patient Information Forum Quality Mark for Health Information - the PIF Tick. Happily we did reach the required standard and are now entitled to use the PIF Tick logo on our information resources, including the website. We will continue to be reviewed annually to ensure that we maintain our standards. We hope that this will give confidence to users of our website, including health professionals, that our information can be trusted for accuracy and reliability.

As a result of achieving the PIF Tick, we are eligible for our information about paruresis and the UKPT to appear on two health-related clinical search engine databases (TRIP and Cognitant), and at the year end this is work in progress. We really hope that this will contribute to a greater awareness of paruresis within the health system.

Media

We continue to post regular social media activity on Facebook, YouTube, Twitter, and Instagram, featuring items of interest to people who experience paruresis, and raising awareness of its existence. In our website review, there were multiple comments from people who said they particularly valued the blogs and being able to read other people’s paruresis experiences.

Finance

We are extremely grateful to our regular donors, many of whom have attended UKPT workshops and have first-hand experience of paruresis themselves. We are committed to raising awareness of paruresis – an ongoing and costly challenge, but one which we are determined to continue.

Our income for the year 2022/23 was £15,473.86.

Our expenditure was £20,261.72

Workshops

We ran 5 online workshops throughout the year, with 34 attendees.

We ran 3 hotel based beginners’ workshops throughout the year, with 25 attendees.

We ran 2 hotel based follow up workshops throughout the year, with 17 attendees.

Online Support Groups

Separate online 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.

Governance

The trustees place the highest importance on having essential and appropriate governance structures in place, including a commitment to ongoing review of all policies and procedures.

In 2022 we registered with the Fundraising Regulator to demonstrate our commitment to fundraising best practice through meeting their Code of Fundraising Practice.

Administrative Officer

We are grateful to our self-employed part-time Administrative Officer 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, reporting on analytics, administering our workshops and playing a key role in the website review.

2023/24

Like everyone else, the UK Paruresis Trust is feeling the effects of the increase in the cost of living as our costs continue to rise. A financial watchful eye is therefore needed going forward.

Andrew Smith

Chair

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