

UK Paruresis Trust Annual Report 2024/25

The organisation was formed in 2002, initially as a charitable association (UKPA), becoming a charitable trust (UKPT) in 2005. We currently have four 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, charitable – in addition to the essential qualities of compassion and empathy needed to help people affected by this difficult condition.

We have the additional support of four Honorary Advisors from the fields of medicine and psychology.

Our trustees are:

Chairman:

Andrew Smith (M.A. Cantab)

Treasurer:

David Winton

Committee Members:

Ann Allcoat LRAM GRSM

Dr Ian Harris PhD

(Peter Daw BSc MSc Clin.Psychol. resigned February 2025)

Honorary Advisors:

Peter Daw BSc MSc Clin. Psychol.

Matt Lane MB ChB BSc MA

James O'Neill Psychotherapist and Psychoanalyst

Jonathon Jones

As 2024/25 draws to a close we can look back and reflect on the work of the UK Paruresis Trust (UKPT) throughout 2024/25.

Every year brings new challenges, new learning, and new partnerships.

Throughout 2024/2025 we have worked closely with [ERIC](#), The Children's Bowel and Bladder Charity.

We know from the many experiences reported by people who attend UKPT workshops that many paruresis sufferers' difficulties arose in childhood. Commonly individuals were bullied in school toilets, leading to years of anxiety around toilets and often developing into paruresis. Sadly things don't seem to be improving much in schools. A recent report carried out by ERIC found that anti-social behaviour such as vaping and bullying around school toilets was causing many schools to shut their toilets during lesson times. Young teenagers report having to choose between either eating lunch or going to the toilet as there isn't time for both; and they avoid drinking during the day so that they won't need to use the school toilets at all.

As disturbing as this for today's school children, we know that it is highly likely to lead to unhealthy toilet habits and many years of ongoing shy bladder issues, including paruresis, into adulthood for some people.

Although UKPT is a UK based organisation, we work closely with the [International Paruresis Association](#) (IPA) based in USA. Paruresis is such a little understood or known condition that it makes sense to share good practice and engage internationally with



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others operating in the same health sphere. Similarly we have supported the [Austrian Paruresis Association](#) as they have begun to develop their organisation offering similar services to UKPT.

Research carried out by UKPT in 2016 indicated that 89% of respondents to a survey of workshop attendees had experienced paruresis for more than 10 years before attending a workshop, with 58% suffering for more than 20 years. UKPT is committed to raising awareness of paruresis in the hope that people will learn about it sooner enabling them to live more fulfilling lives unrestricted by the limitations of paruresis.

Trustees and Volunteers

All trustees and workshop leader volunteers have had 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, 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, 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.

Peter Daw stepped down from the Trustee board just before the end of the year. We were delighted, however, 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 a record 17,000 people visited the website.

We are indebted to our website design company, [Light Bulb Web Design](#) for their sensitive and timely support with our website needs. Also to [Climb High SEO](#) for their support with our Search Engine Optimisation needs.

The internet is still the way that 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 2025/26 may help to increase that 4%.

Throughout 2024/25 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.



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Awareness Raising

Throughout 2024/25 we have been working towards the development of our “Breaking Free from Paruresis” training project. In January 2024 we were awarded two-year funding from the National Lottery Community Fund to fund the development of our two training sessions for Health Professionals and Therapists.

The [two online training sessions](#) have both been awarded Continuing Professional Development accreditation from the [CPD Certification Service](#). We hope these will contribute to enabling healthcare professionals and therapists to be more confident in their interactions with their patients/clients with paruresis.



We continue to post regular social media activity on Facebook, YouTube, X, and Instagram, featuring items of interest to people who experience paruresis, and raising awareness of its existence.

We've featured two podcasts of people talking about their paruresis experiences, and some blogs on subjects such as “Dealing with setbacks”, “Changed your mindset recently?”, “How big is your personal space?” and “Is paruresis curable?”

We have begun to publish a quarterly online newsletter featuring items of paruresis-related interest, workshop dates, feedback etc.

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 November 2024 we were delighted to be awarded £2,000 funding from the [Hospital Saturday Fund](#) to enable us to offer financial assistance to people wishing to attend a workshop, but lack of money is preventing them.



Our income for the year 2023/24 was £ **23,793.42**

Our expenditure was £ **24,471.01**



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Workshops

Our workshops are the cornerstone of our activities. The self-help format has been tried and trusted for over 20 years. Individuals are supported by trained volunteers who have themselves worked through their own paruresis. However, we don't rest on our laurels. We constantly review the workshop content and outcomes for individuals, ensuring that our material is current, and changing nuances and explanations if we find better ways to express them.

At workshops we seek out volunteers who show potential to become workshop leaders. We offer training to interested individuals, allowing us to expand our capacity in the future for delivering workshops.

We ran 2 online workshops throughout the year, with 15 attendees.

We ran 4 beginners workshops throughout the year, with 32 attendees.

We ran 2 follow on workshops throughout the year, with 22 attendees.

We ran 1 combined beginners/follow up workshop in Scotland, with 4 attendees.

Here are some of the phrases which have featured in recent feedback from workshop attendees when we asked how much they had improved compared to what they had expected, and overall impressions.

"Positive mindset."

"More confident, weight off my shoulders, more relaxed, less stressed."

"Thank you so much for providing this support. It's so reassuring to know there's a supportive community I can rely on."

"Really helped me feel in control."

"Excellent, compassionate and caring."

"Very happy that I came and am proud of myself for going outside my comfort zone."

"Better than expected, made some great progress."

"Thank you for organising a workshop - the best way to cure and control paruresis. 100% well done."

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 a pee buddy for each other to practice desensitising.

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, and trustees are able to offer online or telephone support to individuals in those circumstances.



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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.

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 (and improvement) of the website, expanding our social media presence, administering our workshops, keeping our various administrative processes in order, and providing a friendly and efficient first port of call for visitors to the website.

2025/26

We're looking forward optimistically to "more of the same" in 2025/26. More people coming to our workshops, more workshops, more visitors to our website, more awareness raising. More people helped to understand, manage, and overcome their paruresis.

Andrew Smith

Chair

PO Box 182, Kendal, Cumbria, LA9 9AE

support@ukpt.org.uk

www.ukpt.org.uk



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