

UK Paruresis Trust Annual Report 2019-2020

The organisation was formed in 2002, initially as a charitable association (UKPA), becoming a charitable trust (UKPT) in 2005. We currently have 6 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 UKPT – organisational, financial, psychological, 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

Peter Daw BSc MSc Clin.Psychol.

Dr Ian Harris PhD

Jonathan Jones

Throughout 2019/20 UKPT has continued to develop its outreach activities building on the achievements of previous years, and constantly scanning the health and voluntary sector for new opportunities to raise awareness of paruresis.

Trustees and Volunteers

Trustees and volunteers 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.

Volunteers who lead or assist at workshops have all had experience of paruresis and have all attended workshops themselves.

Volunteers who are trustees, some also being workshop leaders, have also had experience of paruresis and UKPT workshops.

Their contribution 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 experience paruresis.

Website

We know from our research on the effectiveness of workshops that 90% of participants discovered workshops through the internet, either by accessing information through the UKPT website, or through use of a search engine. It is extremely important therefore that our website is an up to date, readily visible and reliable source of information about paruresis and the UKPT.

We continued to develop our website www.ukpt.org.uk throughout 2019/20 on an ongoing basis, ensuring that all information was accessible through search engines and links to other organisations, taking into account valuable feedback from workshop attendees and volunteers.

We have worked on a number of “backroom” aspects of the website, improving search engine optimisation. We have also begun to develop areas of the website with articles and information for health professionals.

Throughout the year, almost 10,500 people visited the website giving us in excess of 44,500 page views.

The National Lottery Community Fund

We were successful in applying to the National Lottery Community Fund in the summer of 2019 for funding to continue our awareness raising activities. These are largely focused on developing the website – improving the language, developing resources for health professionals, continuing to develop our social media presence and maximising relevant contacts. A new project for 2020 will be the development of a youtube presence accessible from the website.

The National Lottery Community Fund (Scotland)

An underspend from last year meant that, with the National Lottery Community Fund (Scotland)'s agreement, we have enough funding to run another workshop in Scotland in 2020.

Finance

The awards from the National Lottery Community Fund have been invaluable enabling us to reach out to try to raise awareness of paruresis. We are additionally extremely grateful to our regular donors, many of whom have attended 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 2019/20 was £21,470. Our expenditure was £23,509.

The (British Medical Association) Patient Information Awards

We entered this competition with our newly designed information leaflets and website. We were absolutely delighted to achieve Highly Commended for the website and Commended for our leaflet “Can’t Go in Toilets When Others are Around?” This enables us to use their logo on our resources and has given us some useful contacts which we hope to be able to take forward as part of our awareness raising activities.

Social Media

We continue to post regular activity on facebook and twitter. Our analysis of the website statistics indicates that those social media channels are often the first step for people finding their way to our website.

Workshops

We ran workshops throughout the year – 3 for beginners and 4 follow up workshops. These were attended by 27 beginners and 23 returnees.

We regularly receive very positive feedback from workshop attendees on the forum.

"I've struggled with this problem since the 1970s and would encourage any fellow sufferers to attend a beginners workshop. If you've already been to your first workshop and are considering a follow-up I can highly recommend it.

The beginners session is totally confidential and non-judgemental, you're surrounded by fellow sufferers as either students or facilitators. I was nervous only for the first few minutes and my progress over that weekend far exceeded anything I could have imagined."

"Just posting on here to share my positive experience of attending the Manchester Workshop in September. The workshop leaders were excellent and meeting others who share the same phobia was really reassuring and motivating. It really does affect people from all walks of life and made me realise that changing our mindset about feeling abnormal is key, when actually it is pretty normal and there are probably even more men out there who suffer with it than we know.

Coming away from the workshop, I felt that I had learned a lot about the cognitive and psychological aspects associated to the phobia, and how and why it happens. Understanding it better has really helped me to think about approaches and try techniques to overcome it."

Women's Group

Some women continue to find it helpful to meet up online with other women experiencing paruresis. Regular Skype meetings help to bring a sense of "not suffering alone" which can help to reduce anxiety levels and give useful experiential tips.

Media

Several media opportunities arose throughout the year giving UKPT the opportunity to bring information about paruresis to a wider audience.

In October 2019 the Irish radio station Go Loud featured an interview with Andrew Smith on their Lunchtime Live programme <https://www.goloudnow.com/podcasts/lunchtime-live-85/lunchtime-live-october-28th-2019-1200-pm-0200-pm-54508>

Also in October 2019 the Telegraph featured an article entitled "Too frightened to urinate in public? You're not alone" where Andrew Smith spoke of how paruresis had affected his life and how many men suffer from the same crippling anxiety <https://www.telegraph.co.uk/health-fitness/mind/men-secret-toilet-anxiety-common-think/>

In July 2019 The Sun ran an article about paruresis, again with input from Andrew Smith. Meet the men so terrified of peeing in public they turn down jobs and won't leave their houses. <https://www.thesun.co.uk/news/9446655/men-terrified-peeing-public-shy-bladder-syndrome-paruresis-public/>

Governance

The trustees place the highest importance on having essential and appropriate governance structures in place. This year we have developed policies and procedures for Data Protection, Privacy and Cookies, and Reserves as well as reviewing existing policies and procedures as appropriate.

Administrative Officer

We are grateful to our part-time Administrative Officer who has willingly taken on everything we have asked of him, helping us to deal with the increasing demands of the administration of workshops, the development of social media, day to day maintenance of the new website, and admin associated with our National Lottery Community Fund awards.

2020/21

As our financial year came to end it began to become apparent that we were entering a time of uncertainty, and as the coronavirus lockdown began to take effect we realised that our spring and early summer workshop activities in England and Scotland were not going to be able to go ahead as planned. At the time of writing it is still unclear how long this situation will last, but the end is obviously not in sight yet.

In the meantime, the website is an even more important source of information for people with paruresis, and trustees are continuing to develop planned activity as far as possible, ready to resume workshops as soon as it is safe to do so.

Andrew Smith

Chair

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