

UK Paruresis Trust Annual Report 2020-2021

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

Towards the end of our last financial year in March 2020 it was beginning to become apparent that the world was changing as the coronavirus pandemic was taking hold. The UK was moving towards lockdown, unbeknown to us the first of three lockdowns which would come to dominate every aspect of life for the rest of our 2020/21 financial year and would still be shaping all our activities as that year came to an end.

We realised early on that our usual spring and early summer workshop activities in England and Scotland would not be able to go ahead as planned. We hoped that autumn 2020 would be able to see a resumption of our activities, but as numbers of covid cases began to rise again we realised that we needed to come up with other ways of supporting people experiencing paruresis.

We looked across the Atlantic to the International Paruresis Association who were starting to run virtual workshops taking place via Zoom. We started our own research to see how that might work in the UK and came up with what we hoped would be a workable model.

Our first trial virtual workshops took place over one day in August 2020. Feedback was very positive and from there we rolled out further virtual workshops every 4-6 weeks.

We look forward to being able to restart our programme of residential weekend workshops in due course as the pandemic hopefully recedes. But we can see that there may be an ongoing place for virtual workshops which take less time, cost less and are easier to access for people living some distance from our actual venues, or for people whose social situation might be such that a virtual workshop remains the method of choice for them.

Trustees and Volunteers

Trustees and volunteers normally 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. This year of course it was not possible for our annual face to face meeting to take place so regular meetings have continued via Zoom.

All trustees and volunteers have had experience of paruresis and have attended workshops themselves.

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

With people spending so much more time online in 2020/21 we were aware of the increased importance of keeping our website up to date, accessible and a reliable source of information about paruresis and the UKPT. Throughout the year, 9000+ people visited the website giving us in excess of 35,000 page views.

We have continued to work towards developing an area of the website with information for health professionals.

We were grateful to the National Lottery Community Fund for the funding provided to continue our awareness raising activities, most specifically the development of a YouTube channel featuring volunteers and/or trustees talking about paruresis and UKPT workshops

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

Finance

We are 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 2020/21 was £5,418.41. Our expenditure was £8423.24.

Workshops

We ran 5 virtual workshops throughout the year, with 17 attendees. We received very positive feedback.

"I am 17 years old and have just taken part in the virtual workshop. Paruresis has affected my life for the past 4 years, as I got older I have found it has gradually got worse and worse to the point where I found myself avoiding social situations. My mum found the UKPT and the workshops they held so I signed up for the virtual one. I am amazed by how much progress I made in just 1 day and I can now really see that I may be able to overcome this problem. All the workshop leaders were lovely and I felt very comfortable talking to them. I am excited to get out there and practice different toilet situations."

"I recently attended a virtual workshop and am amazed at how positive I now feel about doing something to help manage my paruresis. I was unsure initially but having read through the workbook beforehand which detailed what would be covered, plus the day's timetable and de-sensing preparation I felt ready to 'face my demons' and go with it."

Once the co-ordinators had introduced themselves I immediately felt more at ease. There was a lot to take in during the day but it served to give an overview of the problem, in order to understand the approach to changing it, and we all had the chance to talk about ourselves and how we are each affected. Many of the stories we shared were so familiar but reminded me again of just how big an impact paruresis has on each of us.

The actual desensitisation was carried out within each person's comfort zone with no pressure and the co-ordinators couldn't have been more sensitive and supportive.

By learning how to manage our anxiety and to rethink our whole approach to weeing, change becomes possible. It's an ongoing approach and we were given worksheets and suggestions on how to continue to reinforce what we'd learnt."

"I attended a virtual workshop of UKPT's last weekend. The workshop leaders delivered the workshop well, and everyone seemed to feel at ease. I learnt many useful techniques that were immediately useful in helping with being able to urinate whilst feeling under pressure, as well as many techniques that I can incorporate into my recovery plan so I can continue to improve. It was extremely encouraging to hear the workshop leaders discuss the degree to which they have recovered; along with the improvements I noticed both during the workshop and afterwards, I now feel extremely optimistic about recovering from paruresis. I highly recommend anyone who is struggling with paruresis to sign up for a workshop as this can be an extremely distressing problem to live with, but through attending a workshop, you can learn techniques to recover."

Women's Group

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

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. The development of virtual workshops has necessitated review of our policies regarding online safety and working with young people,

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 development of new procedures around virtual workshops, the development of the YouTube channel, day to day maintenance of the website, and all general admin.

2021/22

At the 2020/21 year end it is still unclear how much the ongoing pandemic will impact on our work going into 2021/22. Indeed it's unclear how much the ongoing pandemic will affect paruresis sufferers themselves. We know that many of them express a feeling of relief that they are not having to worry about social activities or can work from home thus reducing the worry of workplace toilets. But they also speak of an underlying anxiety about how their paruresis will be when the time comes to leave their enforced isolation and get out into the world to interact with other people again.

Virtual workshops will continue while there is demand for them, and we are committed to resuming physical workshops as circumstances allow.

Andrew Smith

Chair

PO Box 182, Kendal, Cumbria, LA9 9AE

support@ukpt.org.uk

www.ukpt.org.uk