

## **UK Paruresis Trust Annual Report 2017/18**

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, medical, 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

Dr Matt Lane MB ChB BSc. MA

When we look back at the development of UK Paruresis Trust in years to come, we shall be able to recall that 2017 - 2018 was a time of significant development for the organisation.

### **Volunteers**

We have always been a volunteer-led organisation and the trend is to increase the number of volunteers to run, or help to run, UKPT workshops. The volunteers have all attended workshops themselves and expressed an interest in giving something back to the organisation. Volunteers are supported through the process of training to take part in the workshops and their contribution is greatly appreciated.

Trustees meet bi-monthly via Skype; we meet in person annually during which volunteer workshop leaders join the trustees for part of the day. It is a very important principle to us that volunteers get to know each other, and have the opportunity to give their views about the organisation and help trustees to drive it forward.

### **Evaluation report**

In early 2017 we were able to complete work on our evaluation report looking back at the outcomes from the 91 workshops we had held to date <https://www.ukpt.org.uk/images/UKPT-Workshop-Feedback-Evaluation-Report.pdf>

114 people who had attended workshops had responded to our survey asking them a number of questions about how the workshops had helped them, and what differences the workshops had made to their lives.

We discovered that most of the respondees had found their way to UKPT via the internet, and that the information contained on the website, along with the discussion board, had been the factors which had influenced them into deciding to attend a workshop. Once at a workshop most of the attendees experienced a significant increase in knowledge, and a decrease in the ways their lives were restricted by paruresis.

Once the report was complete we sent it to the British Association for Behavioural and Cognitive Psychotherapies (BABCP) and were able to make contact with therapists and counselors who have some experience in treating people experiencing paruresis. Their details are now available on the website for people who wish to make contact with them directly themselves.

## **Website**

Having some clear evidence of the effectiveness of our workshops enabled us to make an application to the Big Lottery Awards for All fund for £10,000 in the spring of 2017. This was successful and enabled us to invest in a new website which would raise our profile on search engines and enable improved performance on tablets and mobiles. The new website (<https://www.ukpt.org.uk>) went live in December 2017. It features men's and women's forums in an up to date format, and a blog facility which links to Facebook and Twitter for news items and promotion of our workshops on social media. We can now take workshop bookings, payments and donations online and have been able to organise and maintain our information in a newly structured way. For the first time we are able to analyse the number and location of visitors to the site - at the 2017-18 year end the website has been visited by around 2000 people from 79 different countries.

## **Finance**

Financially the award from the Big Lottery has been invaluable for the organisation. But we continue to rely on the goodwill of our regular donors, many of whom have attended workshops and have first hand experience of paruresis themselves. We are tremendously grateful to them. Raising awareness of paruresis is an ongoing challenge, a costly one, and one which we are determined to embrace.

Our income for the year 2017 – 2018 was £17,614 and our expenditure was £15,818.

## **Virtual Reality**

In June Andrew was contacted by Agni Paul, who was doing a one year, full-time research degree at Nottingham University (MRes) on the use of Virtual Reality as a tool for desensitisation by people with paruresis. Agni had initially made contact with Professor Soifer in the USA, who passed him on to Andrew, being UK based. Agni explained that Virtual Reality had been used successfully in treatment for social anxiety. The aim of his research was to test the validity of Virtual Reality as a form of exposure therapy for people experiencing paruresis. The intention was to develop a mobile app which would provide a series of scenario steps based on cubicles and urinals, the former being usable by both men and women. Agni's main request was for subjects to test out his virtual reality prototype once developed. We were happy to accommodate this and workshop attendees, trustees and volunteers all took part in the testing.

Agni is currently hoping to develop his work into a PhD.

## **Workshops**

During the year we began to make progress planning our first workshop in Scotland which will take place in the summer of 2018. We also changed our regular southern venue to Reading in response to feedback that the central London venue was difficult to access and not ideal in terms of nearby facilities.

We ran 9 workshops throughout the year – 6 for beginners and 3 follow up workshops. These were attended by 41 beginners and 19 returnees. We were particularly pleased to have been able to develop processes to allow younger people to attend the workshops. Two people below the age of 18 attended and feedback that they found it very beneficial. Our evaluation report had identified that 89% of all respondents had experienced paruresis for more than 10 years, and 58% for more than 20 years. Accordingly we place a particularly high priority on being able to reach people as early as possible on their paruresis journey.

We regularly receive very positive feedback from workshops on the forum. One attendee had this to say: *"We got a whirlwind of facts, ways of dealing with every obstacle that would arise, and a clear idea of how to go forward so that we would no longer live under the shadow of AP. We also rocketed from where we thought we were in our different forms of AP to a completely new place. I left feeling quite confident that the turmoil from this would end."*

*I can't go through everything, but I came to it uncertain of what to expect. Through much discussion and water, we came out of our different mental shells--or it would be more accurate to say those mental shells were hit with a sledgehammer and broken--and began making progress getting more comfortable with toilets at a rate we would never have thought possible 24 hours before. We had a whole host of negative feelings about toilets and going there, but we were able to identify them and through the various tools and tips this workshop offered we got substantially better--we're still clearing out the debris, naturally--Rome wasn't built in a day--but I'm quite certain now that I can get out of it now to a place I'm happy if I keep at it, practicing with all the tools and tips offered."*

Other comments include *"I'm finally making headway on this 30 year old problem/phobia"* and *"I can absolutely say that attending the Manchester workshop was the best decision I've made."*

## **Governance**

The trustees place the highest importance on having essential and appropriate charitable structures in place. This year we have developed policies and procedures for working with under 18's with a robust policy on Safeguarding Young People and Vulnerable Adults proving its worth.

## **Administrative Officer**

We have taken on the services of a part-time paid administrative officer to help us to deal with the increasing demands of the administration of workshops, and the development of a social media presence linked to the new website.

## **2018/19**

The International Paruresis Association (USA based) tells us that around 7% of people live with some degree of paruresis, many of those suffering for 20+ years before trying to seek help for this distressing condition. UKPT will continue in 2018/19 to work towards reaching as many affected people across the UK as early as possible in their paruresis experience using a variety of methods - website based information, weekend workshops, articles, social media and promotional activity. We look forward to updating you on future activity in due course.

Andrew Smith

Chair

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