

## **UK Paruresis Trust Annual Report 2018-2019**

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 - stepped down in October 2018

Jonathan Jones - appointed in November 2018

2017 - 2018 had been a time of significant development for UKPT. It's very satisfying to see that 2018 - 2019 has continued in much the same way with new developments, increased numbers of volunteers and increased outreach activity.

### **A tribute and heartfelt thanks to Alex Gardner**

We are sad to record Alex Gardner's death in late 2018. Without him there would have been no charity, no workshops, and hence none of us, let alone 100s of others, would have had their lives changed. Alex was a retired Professor, a Chartered Psychologist, and a Registered Psychotherapist. He brought enormous experience, and a larger than life, extravert and friendly approach to the aid of the group of men which was to become UKPT.

Compared to where we were in 2001, a group of unhappy men with a condition that no-one knew about, Alex's energy and commitment put the condition into the public view, and also into the professional arena.

He remained an honorary advisor to UKPT until recent years and is remembered by his presence at every beginners workshop, large as life, on our opening DVD.

Visit the website for a more detailed obituary <https://www.ukpt.org.uk/images/Professor-Alex-Gardner-obituary.pdf>

### **Trustees and Volunteers**

It has become a regular event for trustees to meet in person annually and for volunteers to join them for part of the time to get to know each other better, 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 have continued to develop our new website [www.ukpt.org.uk](http://www.ukpt.org.uk) throughout 2018 - 19. We recognised that having a new website built in 2017 - 18 didn't mean that it could remain a static internet presence, and that it was important to continue to develop the website in response to feedback from workshop attendees and volunteers.

We have improved a number of aspects of the website enabling easier access from mobiles, simplifying the workshop booking process, streamlining Gift Aid giving, improving access to therapists.

Throughout the year, around 10,000 people have visited the website.

### **Big Lottery Awards for All (now the National Lottery Community Fund)**

Further to our success with funding from the Big Lottery Awards for All fund in 2017 - 18 we re-applied in summer of 2018. At this stage the funding priorities had changed and we applied under the priority of "*enabling more people to fulfil their potential by working to address issues at the earliest possible stage.*" We knew from workshop attendees that many people had first experienced paruresis in their childhood or student years and suffered with it for many years before they finally discovered UKPT and attended a workshop. We therefore applied for funding to increase our outreach activity, most specifically targeting university student support/health and wellbeing departments to raise awareness of paruresis and our workshops. We were successful, being awarded £10,000. The funding enabled us to offer students a discount for the duration of the project in order to encourage more of them to self-identify and come along to a workshop, hopefully before paruresis had had too many damaging effects on their mental health, career choices and social activities.

With the help of our volunteers we reviewed our leaflets and developed a series of posters particularly suitable for the back of toilet cubicle doors or student notice boards. We also increased our social media activity in order to try to appeal to student communities.

### **Big Lottery Awards for All Scotland**

In September 2018 we ran our first workshop in Scotland. This was attended by 7 people and, encouraged by this, we applied to the Big Lottery Awards for All in Scotland to run a similar project to the one we were proposing in England ie approaching universities to raise awareness of paruresis, encouraging students to self identify and apply for places at a Scottish workshop. We were successful, being awarded £6,260.

## **Finance**

The awards from the Big Lottery have been invaluable enabling us to reach out to try to raise awareness of paruresis. 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 extremely grateful to them. We are committed to raising awareness of paruresis - it is a big challenge, and a costly one, but one which we willingly embrace.

Our income for the year 2018 – 2019 was £28,935, of which £16,200 comprised lottery grants. Our expenditure was £26,676.

## **Outreach**

We were in discussion with a number of like-minded organisations during the year.

We were already members of the [British Toilet Association](#) and had several discussions to increase our mutual understanding and highlight the areas of interest to people with paruresis. Further to these discussion we made contact with the organisers of the [Loo of the Year Awards](#) and manned a stand at the annual event where the best washrooms in the UK are recognised and rewarded.

We entered the [BMA \(British Medical Association\) Patient Information Awards](#) with our newly designed information leaflets and website.

## **Virtual Reality**

In last years annual report we gave details about the virtual reality project underway by Agni Paul, supported by UKPT.

### **The Paruresis Virtual Reality Project (PeeVR)**

The idea of designing a Virtual Reality (VR) based study was first conceived in the mind of Mr Agni Paul, a Computer Science Masters student and Researcher from Nottingham Trent University. His aim was to test the effectiveness of VR in paruresis and also to create a low cost immersive treatment application to help individuals test their fear, within the safety of their home. After several meetings and discussions with the International Paruresis Association (IPA) and UKPT, he designed and developed a 3D restroom environment to test on individuals suffering from paruresis.

In October 2017, Agni conducted the first VR Paruresis pilot study in the world, with the support and supervision of UKPT. A Samsung Gear VR wireless headset was used to simulate an interactive public restroom with various levels of anxiety triggers. Each individual's anxiety levels were recorded, and a feedback discussion was also conducted to determine any further improvements which needed to be implemented into the software. On 4th September 2018, the findings of the study was presented and published at the ICDVRAT (International Conference on Disability, Virtual Reality and Associated Technologies) conference. The novelty of the research was critically appreciated by researchers and sufferers alike. Agni hopes to be able to prove its effectiveness through a Doctoral study and at this point the research is only limited by the absence of necessary funding.

## **What is next?**

The next step of the research will further develop and investigate the potential to utilise a VR or MR (Mixed Reality) application as a form of exposure therapy. Improvement of an individual's condition substantially depends on the individual carrying on the graduated exposure after the workshop; this is difficult for most due to the lack of suitable opportunity, a problem which this low cost VR intervention can potentially solve.

Based on the individuals' feedback, Agni and the UKPT are working on adding new functionalities and environments to the existing software prototype. A second environment (an airplane toilet, that has been tested by the UKPT board of trustees) and a third (a motel room/ restroom) has already been designed, and awaits the opportunity of being tested by individuals.

With the launch of better VR and MR hardware in 2019, this study holds a lot of potential to help tech savvy individuals take the early steps in battling paruresis.

You can find more information and a copy of the report at [J Lewis, A Paul and D Brown \(2018\): An exploratory investigation into the potential of mobile virtual reality for the treatment of paruresis - a social anxiety disorder.](#)

## **Workshops**

We ran workshops throughout the year – 6 for beginners and 4 follow up workshops. These were attended by 45 beginners and 22 returnees. Last year we had developed safeguarding processes to allow younger people to attend the workshops and this proved beneficial again in 2018-19.

We regularly receive very positive feedback from workshops on the forum. One attendee had this to say: *It was a liberating experience to be with people who all shared the condition, no need to constantly be on your guard and pretending it doesn't exist, not always checking to see who's going to the loo and whether there will be sufficient lull to dare go yourself. The empathy from the others there gives you a lot of reassurance. It's hard work but it's manageable and although I was stressed, at no point was it overwhelming.*

*By the end of the Sunday sessions I was feeling that I'd made more progress in one weekend than I'd have dared to predict. Hard to believe, but I'd actually enjoyed much of the weekend. I think if it had been longer I might have overcome my AP. As it was, I felt I'd made a huge step forward and for the first time in a very long time, I hadn't felt ashamed of having this condition. I'd recommend to anyone wavering as to whether or not to attend a workshop, to grab the opportunity. Everyone who attended mine felt they'd made good progress over the weekend. Some felt well on the way to getting it under control.*

## **Women's Group**

All evidence would indicate that far more men experience paruresis than women. Nevertheless, women can be affected but seem far less likely to identify themselves than men. We have no way of knowing how many women experience paruresis symptoms but just put up with them, believing themselves to be the only person in that situation. A small group of women came together initially via the website forum, then began to exchange emails and "meet up" virtually from time to time via Skype. Some of the women were able to meet together in London in the summer of 2018 for mutual support and information.

## **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, Conflict of Interest, and Managing Volunteers 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 Big Lottery funding awards.

### **2019/20**

We know from the many paruresis sufferers we have spoken to and listened to over the years that the condition is little known and little acknowledged. Many people suffer for years before even coming across the word "paruresis". Once they know what it is called, it is easier to find help thanks to the internet, and UKPT is committed to reaching as many people with the condition as possible. Our workshops remain the keystone of our work across the UK, and we look forward to another year of raising awareness and helping people whose lives can be transformed once they know there is help available and where to go for support.

Andrew Smith

Chair

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