

## **UK Paruresis Trust Annual Report 2021-2022**

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

### **Honorary Advisors:**

Peter Daw BSc MSc Clin. Psychol.

Matt Lane MB ChB BSc MA

James O'Neill Psychotherapist and Psychoanalyst

With the UK still under covid restrictions throughout much of our 2021/2022 year, we continued to offer our programme of virtual workshops throughout 2021/22, revealing some unforeseen benefits. We found that virtual workshops often attracted younger attendees than physical workshops, several being under the age of 18; they attracted more women than would normally attend physical workshops; they attracted people who had limited time and limited finances to be able to attend a weekend physical workshop; and they also attracted more attendees who were quite severely affected by paruresis and for whom the journey to attend a weekend workshop would be a challenge in itself.

As the 2021/22 financial year drew to a close we began to see that we could begin to plan ahead to hold physical workshops again. But given the positive feedback from virtual workshops and the way in which they have opened the organisation up to people who may struggle to attend physical workshops, it was decided that virtual workshops should continue to be part of our ongoing programme of events.

### **Trustees and Volunteers**

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

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 it was once again not possible for our annual face to face meeting to take place, so regular meetings have continued via zoom.

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 experience paruresis.

Two of our trustees are featured telling their paruresis story on our YouTube channel which was launched in the summer of 2021 <https://www.youtube.com/channel/UCtDNrEPtcvCTXcGTAotFliQ>

### **Honorary Advisors**

We are indebted to our honorary advisors who give their expertise as required. We are delighted that James O'Neill Psychotherapist, Psychoanalyst and author of "Undressing" (Shortbooks, 2019) joined us in 2021.

### **Website**

Throughout the year, 14,000+ people visited the website giving us in excess of 48,000+ page views.

We are once again indebted to the National Lottery Community Fund for providing funding to enable us to carry out a substantial review of the website. This started just before end of the 2021/22 financial year and will probably take several months to complete.

We know that our website is the way in which most people first encounter the UKPT, and we are committed to making sure it is up to date, accurate, and as user-friendly and accessible as possible. The quality of the information we provide on the website is of paramount importance. With that in mind we decided to work towards the Patient Information Forum Quality Mark for Health Information - the PIF Tick. The Patient Information Forum is the UK membership and network for people working in health information and support, and achievement of the PIF Tick will demonstrate that our information processes are robust and reliable. At the year end we are awaiting the outcome of our assessment to see if we have reached the required standards.

Should we be successful, we hope that this will give confidence to users of our website, including health professionals, that our information can be trusted for accuracy and reliability. We are indebted to the National Lottery Community Fund for extending funding to enable us to carry out the work that this has involved.

We were delighted to be able to share on our website a set of seven videos developed by Martin Burrige, a former therapist who used to treat people with anxiety disorders, including paruresis. Martin developed the videos for YouTube. They give information on how Cognitive Behavioural Therapy techniques can help people with paruresis, and he generously agreed that we could additionally feature them on our website.

<https://www.ukpt.org.uk/living-with-paruresis/shy-bladder-videos>

### **Media**

We've been featured in several media publications during the course of 2021/22. The British Medical Journal worked with us to produce an article in the "What Your Patient is Thinking" series focussing on GPs and helping them to understand more about conditions which they perhaps rarely encounter, such as paruresis. <https://www.bmj.com/content/375/bmj.n2197.full?ijkey=Asq0iaDnKAZ8PYx&keytype=ref>

The Daily Mail published an article featuring Ian Harris's paruresis experience and how his life was turned around after attending a UKPT workshop.

<https://www.dailymail.co.uk/health/article-10365571/The-embarrassed-millions-blighted-shy-bladder.html>

A similar article subsequently appeared in the Irish News.

<https://www.irishnews.com/lifestyle/health/2022/01/20/news/the-embarrassed-millions-blighted-by-shy-bladder--2561030/>

We continue to post regular social media activity on Facebook, YouTube and Twitter, and now Instagram too, 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 UKPT 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.

We are once again very grateful to the National Lottery Community Fund for their financial support which is invaluable in enabling us to take our work forwards.

Our income for the year 2021/22 was £20,479.99 of which £9,100 was from the National Lottery Community Fund and was largely yet to be spent at the year-end.

Our expenditure was £7729.25

## **Workshops**

We ran 8 virtual workshops throughout the year, with 56 attendees. We received very positive feedback:

*"The workshops show you that there is a way to improve the severity of a shy bladder and they provide you with all of the knowledge that you need to go about improving your life. Anyone who wants to get better should sign up - there is nothing but positives to be gained from attending."*

*"This is the perfect environment to start working on our condition. There is a mixture of theory and personalised exercises. While the leaders are not medical professionals, they have plenty of experience, knowledge and interest in the topic. The methods we learnt seem applicable to real life situations. What I particularly liked was honesty and emphasis on real progress, achievable goals and preparation for setbacks."*

*"My progress definitely surpassed all my expectations.... I'm way more optimistic about my recovery....now I know that I can overcome it, that's a big relief"*

## **Online Support Groups**

Our women's online support group continues to provide women with an opportunity to meet up on zoom with other women who live with paruresis. 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 women are facing similar difficulties in their lives.

During 2021 we started a monthly online support group for men who have attended workshops, and this too has continued.

## **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. In the summer of 2022 we carried out an audit of all policies and procedures to ensure that we are really doing in practice what we say we will do in theory. It was satisfying to note that as a consequence very few alterations were needed to our working practices.

## **Administrative Officer**

We are grateful to our self-employed part-time Administrative Officer who has willingly taken on everything we have asked of him - contributing to the work involved in the PIF Tick, day to day maintenance of the website, expanding our social media presence, reporting on analytics, administering our virtual workshops. At the year end as we are starting to review our website, the Administrative Officer has been playing a key role in gathering feedback and planning our work going forwards.

## **2022/23**

**Just as the 2021/22 year ended so did most of the covid restrictions. Life is not yet back to "normal" but it is clear that we can now begin to make firm plans to restart our programme of physical weekend workshops in 2022. At the year end we already have significant interest being shown in these. It will be good to work with our volunteers in person again, and to interact fully with workshop attendees.**

**The Website review is imminent and we are already starting to formulate some ideas to take us forward, whilst not losing the aspects of it that are still working well.**

**Trustees and volunteers look forward to being able to meet in person towards the end of 2022 for the first time since 2019, to review the organisation's ongoing activities and plan ahead.**

Andrew Smith

Chair

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