

## newsletter

### uk paruresis association newsletter – june 2003

*This newsletter makes reference to UKPA, the trusts former name. The only updated edit is our email address.*

Because people understandably do not or cannot read the website's bulletin board on a regular basis, it is not the most reliable way to disseminate information. Hence we are sending you this e-zine, to inform you of what has and is going on in the UK.

A lot has happened since the Association was set up at the Support Group meeting in Birmingham in July 2002. To provide a context, some of the work done before becoming an organisation will be described. Hence this newsletter is very long – the following ones will be more snappy!

Probably the most significant is our success in obtaining charity status in December 2002. With that goes renewed confidence in moving forward with the aims of the Association. Our charity number is 1095109.

Another is our success in raising a small membership, and in raising enough funds to allow the Association to continue. Our annual income is now about £1800 and we have 23+ members plus several more benefactors who are not members.

Yet another success was the first weekend residential workshop held by the UKPA, more on this below.

The work is described as follows against each aim of the Association.

### **the provision of internet based information and support**

The website and the bulletin board continue to play an important part in enabling people to make contact with the Association, to find out more about the condition, and to seek support. We are fortunate in having a skilled webmaster, who ensures the site is technically sound without becoming unnecessarily technically complex. The website has been revised and brought up to date, more information has been provided, including a First Timer's guide, and the site is more focused than it was. However the process of reviewing the content is ongoing.

Thankfully since June 2002 there have been no occurrences of abuse or inappropriate postings on the bulletin board. However the board is still monitored daily, both for this reason and to ensure that all postings are answered. The moderators of the board are now the Committee, the webmaster and one of the original group who set up the site.

Thanks to the webmaster, the facility to email from the website to [hello@ukpt.org.uk](mailto:hello@ukpt.org.uk) is being used

steadily. He is also taking steps to make the site visible to search engines, via a range of appropriate key words. Another priority is to ensure that the pages download quickly, to make it easier for surfers to download the site's full set of pages.

## **the promotion and provision of local support groups**

Prior to setting up the Association, the first national support meeting for a year or two was arranged for Warwick in April 2002, which attracted six people. The attendees requested a further meeting, which took place in July in Birmingham, attracting 13 people. Due to the success of that meeting, it was decided to try regional meetings. Hence September/early October saw meetings in London, Manchester and Bristol.

The London meeting attracted 8 new people, one being female. Manchester and Bristol five new people each.

These figures were somewhat disappointing, but on reflection were seen as evidence that people with AP are a cautious lot, and need time to get used to the idea of meeting with others. Some find the idea too nerve-wracking and drop-out, which is understandable. This emphasises the need for sensitivity when making arrangements. After a time organisers can become blasé, but for newcomers it is still can be a fraught experience to walk through the door. However they are always glad to have attended.

The London group requested a three-monthly meeting, and hence has met in February and May 2003. The Bristol group opted for two monthly and met at the end of November. This comprised only two people other than the two organisers, but one of the new ones had come from Essex! It has not met since.

It was decided for the meantime to have two groups: a southern meeting in London and a northern meeting in Manchester, both on a three monthly basis.

The UKPA is open to requests to plan a meeting in other areas. Contact Andrew on [hello@ukpt.org.uk](mailto:hello@ukpt.org.uk), or by mail at the address below.

## **the provision of weekend residential workshops**

It was decided to postpone any workshop until the Association had gained charity status. That was acquired just before Xmas 2002, and the first UKPA workshop took place in March 2003, co-led by Andrew Smith and Professor Alex Gardner, who is a chartered psychologist and psychotherapist. Twelve men participated and experienced the intensive cognitive-behavioural therapy necessary to tackle this condition. Sample reactions were:

*I don't think you can overestimate the impact it has had on some of our lives. Its definitely given me the kick-start I needed, I now have the "belief".*

*It fully met my expectations and beyond.*

*I did not expect to meet such a great bunch of NORMAL guys – maybe I'm also normal!*

*I managed to urinate in situations I would have previously never managed.*

However being aware that participants can easily regress when left on their own, the decision was taken with them to have a series of follow-up workshops, with on-tap support in between, in order to keep up and build upon the progress made. Our aim is to take these participants through to the point where AP ceases to be a controlling factor in their lives. If we can achieve this, we shall have a proven methodology, and can then work then on shortening the timescales and costs. These sessions would be for the original participants only.

For newcomers wishing to take part in a workshop, we plan to start a second "class" in the Autumn; if you are interested contact us.

## **the promotion of the concept of individual privacy in the design of public toilets**

For the record, Professor Gardner (see below) and Andrew Smith attended the *British Toilet Association's* annual conference in May 2002. Professor Gardner obtained a speaker slot and used it to introduce the conference to Avoidant Paruresis, and hence the need for more privacy in the design of Public WCs. The catch phrase LISP (Line of Sight Privacy) was coined for the occasion. From the attendance of 100+, two men came forward afterwards to tell us of their AP. Very usefully, contact was made with the Chief Executive of the *Centre for Accessible Environments* (CAE), who expressed interest in finding out more.

As a result of that contact, an agency employed by the CAE to revise its guidelines for Public WCs contacted us in January 2003 to solicit advice on how to include our requirements in its document. This was achieved co-operatively and successfully.

Following on from this, because we had given a specific *JD Wetherspoon* pub as an example of premises with very AP friendly toilets, the agency contacted *JDW*. At their request, we met up on location with a *JDW* photographer in order to take photos of the toilets to illustrate the design points we had made. *JDW* expressed interest in writing an article for their in-house magazine about how the toilet design helps APs – this has appeared in their June/July issue on page 11.

Coincidentally at the same time a sanitary ware manufacturer found our web site and contacted us for information. A fruitful discussion ensued, and he indicated he would use our ideas when making his presentation to architects, of which he does 20-30 each year.

*The British Toilet Association* has since offered us membership. As they organise an annual *Toilet of the Year Award*, this would enable us hopefully to influence the design criteria used in assessing installations for the award.

## **the promotion of research into all aspects of the condition, particularly its cause and treatment**

Professor Gardner designed an anonymous questionnaire, which was piloted at the March workshop. His aim is to refine it and then issue it to you dear reader, in order to build up statistically analysable data – the first ever in the world to our knowledge.

All postings on the board are being archived, so as to be available for any approved research purposes.

## **the raising of public awareness, including that of the medical profession**

Back in 2001, several people posting on the board were wondering how we could get radio exposure – no-one even considering “coming out” on TV. Then a TV production company approached the board for people to interview for a light “hip” series on toilets. Andrew Smith volunteered, and the resulting 2 minute slot was a severe disappointment. Because of his media inexperience, he came over in a negative way. However the silver lining to this cloud was meeting with Professor Gardner on the day of the shoot, which led to his active involvement with us as a consultant, a psychologist, a therapist and as a media personality – he is a member of the *Association of Broadcasting Doctors*. It is fact that without his encouragement and advice we would not be where we are today.

In 2002, due to his efforts, he and Andrew Smith have been interviewed on *Radio 5 Live*, Birmingham local radio and *BBC Radio London* – all being late night phone-in magazine programs interviewing live by phone. These have all been successful – the interviewers being open minded and understanding, allowing AP to be portrayed in a positive way, and so promoting contact with new people.

The highlight however was the interview on the *Richard & Judy Show* for *Channel 4 TV* in June 2002. Professor Gardner, Baz Chalabi and Andrew Smith were interviewed in the studio for about 10 minutes. The result was 70+ letters and an estimated 200 people hitting the website.

The Professor has taken any opportunity he can to bring AP into the light. An example was an article for *the Scotsman*.

With respect to the medical community, it was felt that any success depended on charity status, and professional validation. Now we have both, we can look at ways to do this.

Our webmaster approached the Home Office via his MP to find out whether they had any policy for dealing with AP in prisons. We now have their official reply (available on the website) which details their policy and the practical instruction to prison staff when applying drug tests (unfortunately there is no mention about the problems of sharing cells). This information has already been forwarded on to two enquirers.

We have sent information to the *John Peel Show*, and to *the Sun's* Agony Aunt, and are awaiting a response. Eventually we shall send information to all the newspapers medical columns and/or agony aunts. A women's column in the *Sunday Express* has already referred readers to our website.

## **conclusion**

We hope that you can take heart that things are moving, albeit at an early stage. You may feel that you would like to attend a support group meeting, and/or participate in a workshop to start the process of facing up to this debilitating condition. If so get in touch.

You may feel enthused to become a member, and/or be a benefactor – a small monthly standing order, when multiplied by a lot of people, soon mounts up to a very useful sum. We particularly would like to build up a fund to help those who for financial reasons would otherwise not be able to attend a workshop.

We would very much like to have some more people prepared to take on small active roles. Any

work is voluntary but by necessity small scale. For instance it would be great to have a women's co-ordinator, who would ensure that women's issues do not get swamped by the more numerous men.

Feedback on this newsletter is welcomed; particularly whether it should be become a regular (but not too frequent) item.

Finally if you do not wish to receive this newsletter, just reply to that effect.

best wishes

***The UKPA committee***