

agm september 2004 – chairman's report

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

the provision of internet based information and support

As reported before, 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 complex technically.

The board is still monitored daily, to guard against inappropriate postings, and to ensure that all postings are answered. A minor case of childish postings occurred in March. The Webmaster traced the origin back to Huddersfield University, and contacted the University about it, giving them the IP addresses and the start and end times of the postings. The University traced it back to specific terminals, and from that to three undergraduates. As result we received an email of apology that oozed embarrassment. We deemed the matter closed at that point.

The facility to email from the website to hello@ukpt.org.uk is being used steadily.

The site is now acceptably visible to search engines, via a range of appropriate keywords.

A gratifying story is that of a female member who attended our London support group. She felt empowered to seek help: armed with our brochure, she was able to get appropriate psychological treatment through the NHS. When summoned to hospital for an emergency eye operation, she gave the UKPA brochure to the consultant, and as a result was treated effectively and sympathetically by all concerned. She has also felt able to request special treatment when travelling, which has made life easier for her. Her story is on the website.

We have surveyed users of catheters to compile a list of what is available, where to get information, and personal experiences of their use.

We have supported an employee whose employer adopted a "provide a urine sample or you are fired" strategy to drug testing. The outcome has been that the employee has been informed by the company that it is looking at "other options" and that, until a decision has been made, the employee will not have to take a urine test. The matter has been passed over to the company's Health and Safety manager, who is fully supportive of the employee's position.

We have supported an individual who cannot urinate away from home and could not get his claim for incapacity benefit accepted. This person's tribunal appeal was successful.

We were contacted by a solicitor on behalf of a client in prison who was due to go before adjudication on a charge of refusing to supply a urine sample. This contact arose because the prisoner had

seen reference to the UKPA in the *Daily Mirror's* column by Dr. Miriam Stoppard. We arranged for Professor Gardner to conduct an assessment of the prisoner. He assessed the prisoner as having a mild case of Shy Bladder Syndrome (i.e. he was able to supply a sample given more privacy). The solicitor stated that submission of the assessment would probably result in the charge being dropped.

the promotion and provision of local support groups

Baz Chalabi organised a chargeable introduction meeting, but due to only two people showing interest, it was decided not to hold the meeting.

It was agreed that we would cease to offer any formal support group meetings, or introductory meetings, and would concentrate on workshops and, as agreed at the previous committee meeting, on encouraging workshop participants to arrange informal gatherings for mutual support.

the provision of weekend residential workshops

Workshops are now being held every two months, alternating a Beginners Workshop with an Improvers Workshop. Following the Beginners Workshop in September 2003, an Improvers Workshop was held in November 2003 in Manchester. The third Beginners Workshop was held in London in February 2004 and attracted thirteen participants, being the maximum capacity of the room. A further three men were on the waiting list. A landmark was the participation of a woman; we were pleased that both she and the men felt comfortable about the weekend. The associated Improvers Workshop took place in April 2004; again the maximum number attended, and came from all three Beginners Workshops.

A Beginners' Workshop was held in June in London attended by 14 men. One was a training professional who was impressed by the professionalism of the arrangements and the presentations. A second was a clinical psychologist, who was very enthusiastic about the methodology. The associated Improvers' Workshop took place in August, attended by 8 – 2 more would have come if not on holiday, and another two had to cancel at the last minute.

A Beginners' Workshop is planned for September; thirteen men have already booked.

Since the inception of the UKPA, forty nine people have attended a workshop.

The workshops are proving to be effective for mild to moderate sufferers. The UKPA is concerned about how to help severe (i.e. home bound) cases.

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

The Centre for Accessible Environments' "Good Loo Design Guide", which contains a section on Shy Bladder and its toilet requirements, has been published. We are delighted that it has been jointly produced by the CAE and RIBA (The Royal Institute of British Architects). This is the sort of respected body that it is very useful to be linked with.

On the same lines, The CAE asked us to write an article for their magazine "Access by Design". The

two page article was included in their Autumn 2003 edition.

In March we made contact with *Viva 2020*, which is a consortium of four universities and thirty partner organisations, that have a five year project to deliver practical tools and resources to support sustainable and socially responsible urban design decision-making. A sub-project is concerned with the *Inclusive Design of Public Toilets in City Centres*. They are interested in our input, and we have contributed to it.

We have made contact with the architect who designed the pub toilet shown on our website. He has agreed to help in revising the design requirements, as expressed in the *CAE Good Loo Design* guide, into the more quantitative format required by *British Standards*. This will enable us to make a submission to the *BS Institute* in due course.

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

There has been no progress in this area, due to Professor Gardner's ill-health. We are pleased to report that he was operated on in early April and has made a good recovery.

As most of you already know, Russell Gibbs, of the *School of Psychology of the University of New England* in New South Wales, Australia, is conducting research into paruresis for a thesis. His web-based questionnaire has been publicised on our website with our full support, and he is gratified at the response. We hope that this study will stimulate discussion in the academic and medical world.

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

That is gradually happening indirectly by our increasing number of contacts.

Our webmaster has been monitoring hits and has found a wide range of institutions, mainly governmental and unions, have been looking.

The implication of the "pee or you're fired" drug testing strategy is being raised with those responsible for advising the government on guidelines and legislation relating to workplace and schools drug testing.

SBS has already been the subject of an article in the *TUC* health and safety publication, and there is the possibility of more to come.

We are in communication with various child-health bodies that are concerned about schoolchildren avoiding school toilets due to:

- ▶ the state of the toilets
- ▶ imposed access restrictions
- ▶ anti-social behaviour therein

The question as to who is responsible for enforcing health and safety standards as regards these issues is being pursued. These bodies are soon to launch campaigns about this.

anxiety disorders conference

We have made contact with Dr David Veale, who is arranging an *Anxiety Disorders Conference* in Manchester in November this year. We asked to be involved and have been given a 90 minute slot. Professor Gardner and Andrew Smith will be the speakers. We hope to benefit from the general promotion, from media interest, and from making contacts with professionals in anxiety related conditions. Their website is www.anxietyconference.org.uk.

drug testing in schools

We have asked the *DfES* about a media report that the Prime Minister had mandated headteachers to make use of urine testing. The *DfES* replied that it was not the case, and that it was up to the individual headteacher to decide whether or not drug testing should take place, and what methods to use.

probation service

Our webmaster has found that the *Probation Service* procedures are inconsistent with those of the *Prison Service*, in that they do not recognise SBS to be a problem and have no procedures or cater for it. As a result of our writing to them, they have responded saying we have raised several interesting issues, and in order to provide an accurate response, they will be responding more fully in due course.

conclusion

The charity continues to meet a need and is well appreciated by those who make contact with it. People and organisations it contacts are usually sympathetic and supportive.