REVIEW OF THE VIRTUAL GLOBAL MEETING OF IC/BPS PATIENT ADVOCATES
5 DECEMBER 2020, ORGANIZED BY THE DUTCH ICP AND IC INDIA

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In 2019 the Dutch IC patient association (ICP) organized a first global meeting of patient advocates following the annual ESSIC meeting in Amsterdam. This year it was decided to hold a virtual meeting on 5 December 2020 in collaboration with the ICI patient association from India, organized by Mathilde Scholtes (ICP) and Balaka Basu (IC India). Around 19 patient advocates took part. The aim was to catch up on developments in the different countries, exchange information between the IC/BPS patient associations and obtain feedback on the impact of COVID-19 on the IC/BPS patients.

Impact of COVID-19

The impact of the COVID crisis had been felt in all countries. Bladder Health UK reported that resources this year have been diverted to COVID which has taken priority over all else. This certainly applies to many more countries. There have been no hospital appointments, treatment has been suspended - with a big impact on instillations - and there are long waiting lists for new patients. While telemedicine is trying to fill the gap, this does not help patients who need hospital instillations. However, in Hungary and the Netherlands many patients are able to do self-instillation so this has been less of a problem. Like other patients with bladder or bowel urgency conditions, IC/BPS patients have been greatly affected by the closure of public toilets during the COVID crisis. This has led to even more isolation. Since COVID has prevented physical meetings of support groups and their boards, online/virtual meetings have been held and are proving a success. In Hungary, a urologists’ IC/BPS training session for 45 participants was planned for April and sadly had to be cancelled/rescheduled.

Issues raised

- Issues raised included the lack of accurate prevalence data in all countries. This data issue has been exacerbated by the name confusion, with multiple names in use, and lack of global consensus on terminology, definitions and criteria. This situation is not only failing to produce accurate data, but also hampering meaningful research. Furthermore, data/statistics play a key role in attracting funding for research. The UK noted that they are having huge problems in getting prevalence data since the IC/BPS figures are combined with other bladder conditions.

- In some countries, including Italy and France, IC/BPS is officially considered a rare disease (and this can sometimes bring treatment benefits) while in others it is considered relatively common, probably because anyone with an unidentified painful bladder condition has been piled onto one miscellaneous bladder pain syndrome heap, often without cystoscopy having been performed.

- In South Africa, they have a problem with IC/BPS not being recognised as a chronic disease and this has an impact on treatment.

- Several patient advocates expressed a concern that some patients may be getting misdiagnosed with IC/BPS when they in fact have some other pelvic pain condition or even a chronic occult infection. In the UK there is a special interest in the role of chronic infection in IC/BPS with a clinic in London focusing on this. In France too there is an interest in the possibility of embedded infection in some patients and trying long-term antibiotic treatment as in the UK.

- Many patients everywhere are unable to afford treatment, the exception being the UK with its National Health System.
- It was felt that there have not been many advances in either research or treatment for the patient in recent decades.

- In Denmark knowledge, expertise and best practices are not being exchanged between hospitals, but this seems to be the case in more countries.

- Denmark and Canada both noted that they are giving more information on self-management / non-medical advice.

- While Canada reported a lack of doctors specialising in IC/BPS with experts retiring and not being replaced, this was echoed in all countries, except India where there has been a massive campaign this year to raise knowledge and awareness among urologists and gynaecologists both in India and surrounding countries with webinars throughout the year. That was at least cheerful news.

- Prohibition of opiate medicines in Canada has caused patients with severe IC/BPS considerable problems.

- The Dutch ICP is fighting for reimbursement of instillations. While Dutch people pay high health insurance premiums, IC/BPS patients cannot get their instillations reimbursed. On the other hand, Elmiron/oral PPS has been approved, but as is currently the case in many countries patients are hesitant due to reports on the risk of maculopathy. While the drug’s efficacy is considered to be limited, it is effective in some patients.

- It is felt that urology societies and government authorities need to be lobbied. IC/BPS is largely being side-lined by the urology societies where the emphasis tends to be on cancer and men’s problems.

- In France, some brand treatments have been removed from the market, instillations are not reimbursed. Here too experts are retiring and there is nobody to take their place. Public research is needed and should not just be left in the hands of pharma.

- Patient advocates want to see more research into the root cause of IC/BPS.

- Serena Bartezzati from Italy and the AICI, who is ePAG Representative for the European Reference Network (ERN) Working Group eUROGEN on urogenital diseases, noted that it is important to have a biobank of IC/BPS patients for research into the cause of IC/BPS. (Further information: Update for ERN Network Board on ERN eUROGEN activities – 2 October 2020: https://eurogen-ern.eu/wp-content/uploads/2020/10/Update-October-2020-Final.pdf. More information also at: https://eurogen-ern.eu/ and https://eurogen-ern.eu/for-patients/workstream-2/interstitial-cystitis/)

- Good news from the UK is that there is a large-scale multi-centre randomised controlled trial in progress at London University, while in the Netherlands a study aimed at demonstrating the efficacy of instillations will start in April. And of course there is also the continuing European IMI-PainCare research project (https://www.imi-paincare.eu/) as well as the MAPP Network in the USA (https://www.mappnetwork.org/). However, more collaboration and cooperation between research centres would be welcome.

A short presentation was also given by IPBF chair Jane Meijlink on the changing role of patient support groups. She stressed that it is now essential to have some kind of global alliance – a central point where support group leaders can obtain help, advice and up-to-date information, as well as moral support for the support group leaders themselves when they find everything getting too much for them – for example they may get burnout - with the risk of the whole support group collapsing which
has happened so often. In addition, as we have seen from these patient advocate meetings, feedback from the different support groups is invaluable since it provides a true picture of the situation at grassroots level.

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