REVIEW OF THE
INTERNATIONAL PATIENT ADVOCATE NETWORKING MEETING
ORGANIZED BY THE DUTCH ICP

Saturday 7 December 2019, Hilton DoubleTree Hotel, Amsterdam

The Dutch IC Patient Association (ICP) took the opportunity to host and organize an international patient advocacy lunch and meeting directly after the ESSIC meeting finished on Saturday 7 December from 12.30 – 17.00. This was a huge success and in addition to patient advocates from many countries was also attended by a number of medical professionals who support patient organizations in medical advisory boards as well as ESSIC Board members. Hopefully this will ultimately lead to some kind of global alliance of patient support groups. Many thanks are due to the ICP and especially Mathilde Scholtes for their hard work in organizing this event and to Dick Janssen MD for kindly chairing the meeting.

The lunch, organized by the Dutch IC Patient Association (ICP), prior to the start of the advocacy meeting was a great networking opportunity attended by more than 30 people and really quite unique in the IC/BPS world. Dick Janssen, MD who chaired the afternoon meeting explained that the purpose of the meeting was for patient advocates to exchange information on the initiatives of their patient association in order to prevent every patient association having to reinvent the wheel. To underline this, the theme of the meeting was “Let’s talk”.

The first presentation was by given by Vicki Ratner, MD and Loredana Nasta, co-chairs of the new ESSIC International Patient Advocacy Committee (EIPAC). Vicki Ratner explained that this Committee was only recently set up and that its mission statement and goals will be formulated in the coming period. The main message is that patient advocates are the key to finding millions of undiagnosed IC/BPS patients around the world and use of the media will be critical in raising awareness. Loredana Nasta emphasized that the idea is to create a virtual network of patient organizations, a kind of umbrella organization, and provide support to the organizations with governance, care and research. The principles of this network are patient-centred care, patient advocate empowerment, and patient engagement to improve the diagnosis and treatment of IC patients worldwide.

Balaka Basu spoke on behalf of Interstitial Cystitis India. Until 15 years ago, she said, it was thought that IC mainly appeared in Caucasian females only. Balaka began the Indian patient organization in 2016 to look for that second patient in India who also had IC/BPS. In the last year, the organization has made great progress in connecting IC/BPS patients within India and even countries around India. Although traditional groups are preferred, much information is exchanged digitally via a Facebook group. A typical local question came from concerned husbands who were unsure whether or not they should leave their wife after she received the diagnosis of IC/BPS. Major problems faced in India include the lack of both awareness among doctors in India and adequate pain medication. A book on Indian Diet for Interstitial Cystitis has been produced by Neelanjana Singh and Rajesh Taneja, published by Avichal Publishing Company.

The Israeli Association for Bladder Syndromes was set up by Yafit Shoval in 2013 and they have now 500 members. The standard of the health care system in Israel is very high with the newest treatments available and medical Cannabis allowed. That does not mean it is easily available to patients as it is expensive and not always covered by insurance. One of the main problems is lack of awareness among medical doctors. Also, only 10 out of 220 urologists are willing to treat IC/BPS patients. Patients feel ashamed and left alone with the disease. Yafit kicked off a big publicity campaign involving a website,
Whatsapp support group, physical workshops for patients, family support groups etc. Yafit also managed to arrange media attention on television, radio and in magazines. A few months ago, she published a cookbook with recipes specifically for IC patients developed by a famous chef entitled “Delicious with IC”. Not focused on what IC patient should not eat, but on recipes for dishes they can eat without problems.

Maureen Morapeli who had travelled all the way from Johannesburg in South Africa came up with the idea to establish the organization named Mpho Ya Lesedi or MYL (which means Gift of Enlightenment). It was formed by six founding members, each with a different specialty e.g. publicity, political connection, financial from which the organization benefits. The purpose is to create awareness of IC/BPS and provide support for those affected by the disease, to promote social cohesion and dignity for people suffering from IC/BPS. Apart from the usual problems of lack of awareness, funding, and research, IC is not regarded as chronic and therefore not covered by medical aid. Patients are not comfortable talking about IC in public due to the stigma still attached to urogenital disorders. MYL entered into partnership with a radio station with more than 500,000 listeners per day for campaigns. MYL also featured in a television program with about 1,8 million viewers. They also have a partnership with Wits University Medical School which supports research into IC/BPS.

IC Foreningen from Denmark was represented by Maria Lukowski. This patient association was set up in 2004 and has currently 88 members. Their mission is to inform members about the disease and create a forum where IC patients can meet and support each other. Its main activity is 3-monthly meetings with fellow sufferers. Patients are keen to have them as the conversations are frank, but the attendance is not as high as expected. New initiatives include a new website, introducing next-of-kin membership and cooperation with the medical staff at the hospital of Copenhagen.

Gloria Romanello represented ACACI, the Spanish patient association for IC/BPS, first established in 2004 and mainly active in Barcelona and surroundings. The aim of ACACI is to assist patients, provide information and create visibility for IC/BPS. There seems to be a challenge as only 232 patients with IC/BPS have been registered in Spain. They have a website, but the use of social media is limited as there is insufficient knowledge among patients on how to use these. They have an ACACI membership card with a picture and signature of the patient on one side and an explanation of IC on the other side, stating that the person has to use the toilet frequently. They would prefer to see a European Federation for IC/BPS, an umbrella organization.

Representing IC/BPS Support Canada was Gail Benshabat (absent in the afternoon and replaced by Balaka Basu), who told us the tragic story of her daughter Lisa who committed suicide in 2016 as she could not bear the IC any longer. For Gail this was the reason to set up IC/BPS Support Canada. The aim is to create a footprint in Canada by providing information and support and create awareness for the disease. They managed to set up a social media support group with over 260 members within five months. There are no statistics available about IC/BPS patients in Canada. It is a big challenge to find doctors who are familiar with the disease, it is difficult to get the correct diagnosis and there is a lack of research.

Vicki Ratner MD founded the ICA, the American Interstitial Cystitis Association, in the USA in 1984 and was president of the ICA from 1984 till 2008. The ICA was the first IC patient association in the world. Today the ICA has an elaborate website with a lot of information which has been an important resource for IC patients around the world. The essential activity of the ICA is the raising of funds, and donations of millions of US dollars are not uncommon. Media (television, radio, magazines, newspapers, social media) play a crucial role in getting the disease recognized by patients and medical doctors. Television interviews generated a lot of publicity for IC. The strategy for a 5-minute
appearance on Good Morning America was to keep it simple, describe symptoms, describe available treatments and identify who to contact for help.

Mathilde Scholtes and Ticky Oltheten represented the ICP, the Dutch IC Patient Association which was established in 1998 by Jane Meijlink and colleagues following support activities in a small informal group since 1993. The association currently has around 500 members. Its Aquarius magazine is published twice a year and with a rating of 8 out of 10 is the flagship of the association. Annual meetings with fellow sufferers, providing information to patients and medical staff and promoting research on IC/BPS are other important key activities. This year the ICP held a patient survey among Dutch IC/BPS patients with 234 people responding. This generated a lot of valuable information on the Dutch patient population. Most interesting was the huge impact of IC/BPS on the daily life of the patients with impairment of sleep scoring highest. In the Netherlands, it is a challenge to get bladder instillations reimbursed. The ICP has been battling against the Dutch government in a court case to this effect. A few weeks earlier, the government approved a research proposal to prove the effectiveness of bladder instillations for IC patients. This should lead to reimbursement of bladder instillations in the future. New initiatives for 2020 are upgrading the website and part 2 of the patient survey which will focus on treatment of IC/BPS.

Ticky Oltheten (ICP) read a personal story indicating the many problems an IC patient encounters and she showed us that these reflect the challenging problems that patient associations are confronted with.

Loredana Nasta is the chairman of the AICI, the Italian IC association, founded in 1995. The prevalence of IC in Italy is 1.9/100,000 patients. The aim of AICI is to spread awareness and knowledge of IC. They work on best practices and have a special focus to build a transnational network and promote a European or International Registry. The AICI actively works to insert IC into the European Reference Networks, which promote adequate treatment for rare diseases. Since 2004, the AICI has had regular television appearances and they have more than 15 interviews on YouTube. They are also very active in research and have a long list of publications on IC. A new initiative is to start building up a tissue biobank as part of eUrogen. Apart from the usual challenges, AICI noted the different clinical criteria for diagnosis, treatment and research.

Jane Meijlink founded the International Painful Bladder Foundation (IPBF), in 2005 together with Dot Milne in New Zealand, Florentina Ferreyra in Mexico and urologist Nagendra Mishra in India. The objective was to keep patients and their organizations updated on IC developments through a newsletter and website, with the aim of increasing knowledge and understanding of IC and its associated disorders. The regular newsletter also gives an update on the latest scientific research on IC/BPS, Hunner lesion and associated disorders. In no time, however, it became very popular with health professionals and the mailing list currently comprises some 4,500 people around the world. The IPBF stimulates and participates in research and also plays an active role in standardization and guideline projects. Another important activity has always been helping new support groups off the ground, helping patients in remote areas to get medical treatment for their bladder problems, and raising general awareness worldwide. For the future, Jane would like to see the new, upcoming generation of patient advocates setting up a completely new worldwide alliance of patient organizations to help and support each other.

While all patient associations clearly have similar objectives i.e. to support patients, provide information and raise awareness about IC/BPS among patients and doctors, they also face similar challenges such as the right diagnosis in the shortest possible time, raising IC awareness among patients and medical doctors, recognition for IC/BPS patients, lack of funds, insufficient research and difficulty to find volunteers to keep the organization running. More than enough reasons to join forces...
to take action together in order to achieve progress for all those who have IC now and in the future. Let’s talk how we can do this!

Closing the meeting, Dick Janssen MD suggested as a first step that the group of participants could stay in touch via email and keep everybody informed about new initiatives of the different support groups and any interesting conferences.

Thanks are due to all speakers for their presentations, to Dr Dick Janssen for chairing the meeting and to the guest attendees for their interest.

*Mathilde Scholtes, on behalf of the ICP*