

ESSIC ANNUAL MEETING 2010

Antwerp, Belgium, 20-22 May 2010.

ESSIC - now transformed from a European to an International Society for the Study of BPS - held its annual meeting in Antwerp this year, at the Radisson Blu Astrid Hotel in the heart of Antwerp's famous diamond district. With sparkling diamonds on display everywhere, it was not always easy for the ladies participating in the conference to keep their mind on the business in hand! Antwerp is also the former home of the famous 17th century painter Rubens and many delegates took the opportunity to visit the Rubens Museum. The conference was organised by Professor JJ Wyndaele and his efficient team from the University Hospital of Antwerp.

This year ESSIC changed its policy and all scientific sessions were open to all registered delegates. The programme included a Fatigue Symposium on Thursday afternoon, on Friday a round table on definitions, a session on questionnaires including new questionnaires being developed by Pfizer and translated into many languages, videos of Hunner's lesions with exceptionally high quality videos shown by Professor Zaitcev from Moscow, a presentation on the morphology of the bladder (Professor M. Cervigni) and scientific presentations by ESSIC members, on Saturday morning a course (partly in Dutch) including presentations by Professor Wyndaele on Therapy and by Dr Joop van de Merwe on exclusion of confusable diseases, followed by a Dutch language Pelvic Pain Symposium in the afternoon which included physiotherapy and osteopathy. The courses on Saturday were exceptionally well attended by multidisciplinary Flemish Belgian delegates.

FATIGUE SYMPOSIUM

The meeting began on Thursday with a Fatigue Symposium. As Professor Nordling noted, little or no attention is being paid to chronic fatigue or tiredness in IC patients. This symposium therefore focused on two viewpoints: 1) the patient viewpoint (Jane Meijlink, IPBF) and 2) the medical viewpoint (Dr Joop van de Merwe, immunologist).

1) Patient perspective

According to the first speaker, Jane Meijlink, the fatigue aspect of IC is still frequently ignored, misunderstood, dismissed as psychosomatic or simply considered irrelevant by many of the medical profession, but it is also equally misunderstood by the patient's family and friends. Fatigue is a potentially disabling condition that can cause mental and physical dysfunction, with a severe impact on the patient's relationships, home-life, employment and social life.

As with everything in IC patients, in fatigue you also find huge variations with a wide spectrum varying from mild and fluctuating at one end of the scale and very severe at the other end, with an impact that may virtually paralyse the patient's life.

One of the aspects that makes fatigue so complex is that persistent tiredness or chronic fatigue can have multiple causes and any given IC patient may be suffering from more than one cause of fatigue at the same time.

Causes of fatigue may include:

- sleep deprivation (lack of sleep e.g. from night-time frequency (nocturia), pain, but also environmental disturbances/noise/light, anxiety/worry, insomnia)
- medication causing daytime drowsiness (or medication causing insomnia and consequently daytime tiredness.
- depression (can cause fatigue, but fatigue can also cause depression)
- impact of chronic pain day in, day out
- various medical conditions and diseases
- autoimmune disease/chronic fatigue

Chronic lack of sleep can cause: fatigue and lack of energy, mood swings, irritability, lack of motivation, decreased concentration, memory lapses, motor performance impairment, disorientation and depression.

Autoimmune fatigue

Autoimmune fatigue (e.g. in SLE, Sjögren's syndrome etc) is rather different to anything else and has no bearing on whether you have slept well or not. You may have neither physical nor mental energy. You become exhausted after the slightest exertion.

With chronic fatigue you have to learn how to pace yourself, learn how to manage physical and emotional stress and above all learn to say no, don't take on more than you can cope with.

It was also emphasised that fatigue impacts not only the patient but the whole family and can cause disruption of the life of everyone in the family. The financial impact of chronic fatigue is also a very important aspect for the patient. People with chronic fatigue may not be able to hold down a job.

2) Medical Perspective

Dr Joop van de Merwe opened his presentation by stressing that chronic fatigue is a phenomenon that is complex, multi-faceted, poorly understood and leads to a severe decrease in quality of life.

Key components are:

- inability to initiate activity
- *perception of generalised weakness, in the absence of objective findings*
- reduced capacity to maintain activity
- *easy fatigability*
- difficulty with concentration, memory, and emotional stability
- *mental fatigue*

Fatigue is considered to be chronic if it has lasted more than 6 months.

It may be:

- *medical*: in association with an organ-based disease
- *psychiatric*: in association with a mental disease
- *idiopathic*: no organ-based or mental disease diagnosed
 - chronic fatigue syndrome (defined for research purposes by restrictive criteria)
 - other (not fulfilling the criteria of chronic fatigue syndrome)

Multidimensional Fatigue Inventory (MFI)

The Multidimensional Fatigue Inventory (MFI) consists of 20 items grouped in five dimensions (facets). The responder indicates on a 1 to 5 point scale to what extent the statement applies to him or her.

(Smets EM, Garssen B, Bonke B, et al. The Multidimensional Fatigue Inventory (MFI) psychometric qualities of an instrument to assess fatigue. J Psychosom Res 1995;39:315-25)

Fatigue Severity Scale Questionnaire

With this patient perspective questionnaire, the patient is asked to circle a number from 1 to 7, depending on how appropriately they felt that the statement applied to them during the preceding week (1: not appropriate; 7: agreement). Scoring is done by calculating the average response to the question.

(Krupp LB, LaRocca NG, Muir-Nash J, et al. The fatigue severity scale. Application to patients with multiple sclerosis and systemic lupus erythematosus. Arch Neurol 1989;46:1121-3.)

Fatigue grading scale

There is also a fatigue grading scale from a doctor's perspective, grading from none to disabling. This is a useful scale applied to cancer patients with fatigue.

(Escalante CP. Cancer-related fatigue: Prevalence, screening and clinical assessment. UpToDate 18.1 (January 2010))

Fatigue in Organ-based Disease

Dr Van de Merwe then gave a second presentation on fatigue in organ-based disease, looking first at cancer-based fatigue and then at fatigue in autoimmune diseases with a focus on Sjögren's syndrome in which fatigue is often experienced by the patient to be the most disabling aspect with a major impact on daily life. This fatigue can be physical fatigue, but also mental fatigue in some patients.

Much more on this subject can be found in Dr Van de Merwe's chapters on Treatment and Fatigue in his book on "Sjögren's syndrome: Information for patients and professionals". Chapter 5 Treatment: www.painful-bladder.org/pdf/ch5.pdf and Chapter 6 Fatigue: www.painful-bladder.org/pdf/ch6.pdf

The speaker concluded by also pointing out that virtually nothing has been published on fatigue combined with BPS/IC. It is regrettably a totally neglected area.

CONTROVERSIES AND DISCUSSION:

Since the ESSIC meeting allowed plenty of time for interactive discussion and many controversial topics were raised, all delegates took full advantage of this opportunity for debate.

Definitions discussion: no global consensus and taxonomy inconsistency

During a discussion on definitions used in different parts of the world, ESSIC chair Professor J. Nordling explained that ESSIC uses the term bladder pain syndrome which comes from the IASP pain syndrome taxonomy for many different pain syndromes. However, it was interesting to note that no single speaker during the ESSIC meeting was using the other pain syndrome terms from this taxonomy, since speakers frequently referred to "vulvodynia" and not the IASP taxonomy term "vulval pain syndrome", nor is the IASP taxonomy term "prostate pain syndrome" (replacing chronic prostatitis) commonly seen either. So the IASP taxonomy issue remains controversial, confusing and is certainly not being used consistently.

Since Professor Y. Homma from Japan was unfortunately unable to attend in person to represent the quite different East Asian viewpoint (Japan, Taiwan and Korea), his slides were presented on his behalf by Professor Wyndaele. This was followed by a discussion on the term “hypersensitive bladder syndrome” favoured as an umbrella term by the East Asian group and which ensures that no patient is excluded regardless of whether they have pain or not. It led to a discussion as to what should be done in the West with the patients who say they have no perception of pain and are often left in a limbo in that grey area between IC and overactive bladder (OAB). According to Professor P. Hanno from the USA, “these patients without pain do not fit into the concept of “bladder pain syndrome””. The question everyone was asking was what do these patients feel if they don’t feel pain? One suggestion put forward was that maybe they feel that their bladder is bursting full when it in fact only contains a few drops of urine? Perhaps it is time to go back and ask the patients! While no real conclusions were reached, it was agreed that more research is needed into the overlap of OAB and IC. However, at the moment it looks as though the new term (bladder pain syndrome) is likely to exclude some patients currently being diagnosed with IC and they may end up with the wrong diagnosis and wrong or no treatment. This is naturally going to be a matter of concern for the patient organisations and many clinicians.

No international consensus and little progress

It was all too evident yet again that there is no international consensus and that, despite years of research and million of dollars, very few concrete facts are really known about this bladder disorder and therefore almost everything that is claimed by the scientists is hypothetical. As Dr Afina Glas from the Netherlands remarked, little seems to have changed since J.R. Hand’s article on IC in 1949!

Furthermore, as noted by Professor Nordling, there is still a clear difference of opinion in many areas of IC between European and non-European countries. So it will be interesting to see how the new International ESSIC copes with this.

No inflammation and no urgency in IC patients?

Speaking at the Saturday morning course, Professor Nordling once again reiterated that ESSIC does not consider BPS to be an “inflammatory” bladder disorder nor does ESSIC consider that this group of patients suffers from urgency (in the sense of a need to rush to the toilet). The latter is rather a controversial viewpoint that most IC patients would probably disagree with!

This discussion made it once again abundantly clear that a) the ICS definition of urgency needs to be revisited and b) more research is needed into different types of urgency and that c) by no means everyone would agree with the above ESSIC viewpoints of no inflammation and no urgency.

PELVIC PAIN SYMPOSIUM

On Saturday afternoon, delegates were joined by several representatives from the Belgian IC patient support group. The afternoon presentations included pelvic pain therapy (Dr A. Glas), pelvic floor physiotherapy techniques (Joëlle Roenen) with advice on how to achieve mental and physical relaxation and recommending an individual approach because all patients are different, and finally a most interesting presentation on osteopathic techniques (J. Quaghebeur).

NEXT MEETING IN MOSCOW

The next ESSIC annual meeting will be held in June 2011 in Moscow and will be organised by Professor A. Zaitcev.

Useful references for fatigue

- Van de Merwe JP. Sjögren's syndrome. Information for patients and professionals. Chapter 6 Fatigue. www.painful-bladder.org/pdf/ch6.pdf
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- Gudbjörnsson B, Broman JE, Hetta J, et al. Sleep disturbances in patients with primary Sjögren's syndrome. Br J Rheumatol 1993;32:1072-6
- Ng WF, Bowman SJ. Primary Sjögren's syndrome: too dry and too tired. Rheumatology (Oxford) 2010;49:844-53
- Segal B, Thomas W, Rogers T et al. Prevalence, severity, and predictors of fatigue in subjects with primary Sjögren's syndrome. Arthritis Rheum 2008;59:1780–7
- Godaert GLR, Hartkamp A, Geenen R, et al. Fatigue in Daily Life in Patients with Primary Sjögren's Syndrome and Systemic Lupus Erythematosus. Ann N Y Acad Sci 2002;966:320-6
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Reviewer: Jane Meijlink

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