

History of the International Society for the Study of Women's Sexual Health (ISSWSH)

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Abstract

The International Society for the Study of Women's Sexual Health (ISSWSH) emanated from a course assembling experts in different disciplines, becoming the model for the society. Seventeen years later the society remains multidisciplinary, with annual meetings featuring state of the art lectures, symposia on controversial topics, and abstracts judged on scientific merit. Educational efforts expanded from a half day precourse to a fall course and another in conjunction with the National Association of Nurse Practitioners in Women's Health annually. Evidence-based conferences have included consensus panels for nomenclature for desire, arousal, and orgasm; pain; genitourinary syndrome of menopause (GSM); clinical guidelines for identification of sexual health problems; and a process of care for the management of hypoactive sexual desire disorder. ISSWSH is now established as the leading organization for disseminating valuable information to providers, researchers and educators regarding management of distressing sexual dysfunction in women.

Keywords: ISSWSH; women's sexual health; female sexual dysfunction; multidisciplinary; desire; arousal; orgasm; pain; GSM; nomenclature

The International Society for the Study of Women's Sexual Health (ISSWSH) is the only professional organization dedicated to women's sexual function and dysfunction. The society was founded less than two decades ago. Therefore, the history of the society is directly linked to the history of the field.

The approval of sildenafil in 1998 by regulatory agencies and a publication in the *New England Journal of Medicine* [1] led women to call urologist Irwin Goldstein to demand a medication for their sexual health problems. There was a paucity of information about the physiology of sexual function and the pathophysiology of sexual dysfunction in

women, but Goldstein wanted to change that. Under the auspices of Boston University School of Medicine, he developed a course entitled New Perspectives in Female Sexual Dysfunction, assembling experts in different disciplines to share their information in an effort to piece together available knowledge. This became the model on which the society was developed three years later.

The course was held in the Boston area in 1998, 1999 and 2000. The first year there were over 200 registrants from around the world. Associated with the 1998 course, the American Foundation for Urologic Diseases sponsored a consensus conference with 19

international experts, resulting in the development of nomenclature for use in women's sexual dysfunction [2]. Prior to this time all nomenclature was based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) of the American Psychiatric Association [3]. With the recognition of biologic components to sexual function, and the need to understand sexual dysfunction in women, the course was lengthened and podium and poster sessions added. Attendance doubled in 1999 with many returning registrants. When queried about interest in initiating a society, the response was negative. The following year, however, the group had an overwhelmingly positive response and the Female Sexual Function Forum was born.

The society was developed in a multidisciplinary manner with by-laws designating that each committee and the board of directors be balanced in terms of gender, geography, and discipline. All disciplines with an interest in women's sexual health would be welcome in the society, with all active members having equal import, regardless of profession, specialty or degree. Many members of the inaugural board continue to be active members, a testament to both the strength of and need for the organization. One of the first society benefits was the start of a moderated on-line forum (ISSWSHNET) for difficult cases that facilitated communication among people from various locations, disciplines, and perspectives. Having gone through multiple iterations, ISSWSHNET remains a benefit for society members.

The format of the first meeting set the tone for future meetings, with state of the art lectures, symposia on controversial topics, and abstracts judged on scientific merit for podium or poster presentation. The hot topic through the first several annual meetings was the use of androgens in women, transitioning later to oral contraceptives and sexual dysfunction. The first business meeting and election were held on 28 October 2000, with Sandra Leiblum voted in as the first president (Figure 1.1).



Figure 1.1 Sandra Leiblum, PhD, first president of the International Society for the Study of Women's Sexual Health, presiding over the business meeting. (See plate section for color representation of the figure)

After a year as the Female Sexual Function Forum it was noted that the word “female” could refer to animals, so, in 2001, the organization was renamed the International Society for the Study of Women's Sexual Health. Alessandra Graziottin from Italy ascended to the presidency but the board remained stable to help the fledgling society. Only active or honorary members could serve on the board or as committee chairs, as affiliate members were associated with industry. The society struggled financially but survived through the fierce passion of the board and the support of its management company.

Nearly 400 people attended the 2002 meeting in Vancouver – the first time this group met away from Boston. Held shortly after the publication of the widely publicized Women's Health Initiative [4], the leadership responded by adding a lunch seminar to disseminate accurate information and help dispel myths propagated by the press. Symposia were designed to span both the biological and

psychological realms in the basic science and clinical arenas. While moving the 2003 meeting to Amsterdam was exciting, it put the society at risk, with a decrease in attendance and increase in meeting costs. Under Cindy Meston's leadership, a development committee was established to seek industry support to help underwrite the conference, as is common among many other societies, with the long term goal of financial stability.

Lorraine Dennerstein put her presidential stamp on the society by recruiting young researchers in an attempt to grow both the society and the field. With the return to the United States in 2004 the society collaborated with the National Institutes of Health, cosponsoring the meeting "Vulvodynia and Sexual Pain Disorders in Women" held the day before the Atlanta ISSWSH meeting [5]. For the first time, several pharmaceutical companies arranged their advisory board meetings around the annual meeting, thus supporting ISSWSH financially and giving increased visibility to the young society. A half-day precourse on the "Practical Management of Women's Sexual Dysfunction" preceded the annual meeting, a response to the increasing demand for instruction for both the novice and advanced health-care provider. The precourse enrollment that first year exceeded expectations with 160 attendees. The board responded by naming an education committee to develop a program of educational courses during the annual meeting, as well as a free-standing three-day course to be held at another time of year.

With these changes ISSWSH was beginning to make its true mark on the field of medicine. In 2005, ISSWSH was under the leadership of its first male president, Stan Althof, and in 2006 the annual meeting moved from October to February, in an attempt to find a dedicated time slot not conflicting with other societies, leaving the October time available for the three-day educational "Fall Course". The rotation of east coast, west coast, Europe for annual meetings would continue for a few years (Table 1.1), until it made more financial sense

to stay in the United States, as attendees and drug development programs were based in the United States, allowing for growth of sponsorship opportunities.

In 2011, the term of president (and consequently both president elect and past president) was changed from one to two years, allowing leadership to develop projects and see them through fruition. With the approval by the Food and Drug Administration of medications for women with various sexual dysfunctions, industry support grew and the society became fiscally sound. The ability to obtain unrestricted educational grants meant the society could fund educational projects outside of the annual meeting. Under the leadership of Andrew Goldstein a new nomenclature for pain was developed in conjunction with International Society for the Study of Vulvovaginal Disease and International Pelvic Pain Society [6], and at a consensus meeting with the North American Menopause Society vulvovaginal atrophy was renamed as genitourinary syndrome of menopause or GSM [7], which is now the accepted term. President Sharon Parish assembled a nomenclature consensus conference to define disorders of desire, arousal, and orgasm [8, 9], and coordinated a meeting sponsored by ISSWSH to ensure these definitions would be considered as part of the new ICD-11 coding [10]. Irwin Goldstein supported the global development committee, securing grants for projects, including a white paper on hypoactive sexual desire disorder [11], and a process of care for the management of women with generalized, acquired hypoactive sexual desire disorder [12]. For the first time, the society was finally able to set aside money in an investment account in 2015 and to use its funds to offer grants to trainees and researchers early in their careers, resulting in future presentations at ISSWSH annual meetings.

With ISSWSH dedicated solely to women's sexual health, other organizations have turned to the society for education. ISSWSH has co-sponsored a course with the National

Table 1.1 Dates and locations of ISSWSH annual meetings and the presidents at that time.

Term	President	Meeting location
2000–2001	Sandra R. Leiblum, PhD	Boston, MA (10/01)
2001–2002	Alessandra Graziottin, MD	Vancouver, Canada (10/02)
2002–2003	Cindy M. Meston, PhD, IF	Amsterdam, The Netherlands (10/03)
2003–2004	Lorraine Dennerstein, MBBS, PhD, DPM, IF	Atlanta, GA (10/04)
2004–2005	Stanley E. Althof, PhD, IF	Las Vegas, NV (10/05)
2005–2006	Anita H. Clayton, MD, IF, FAPA	Lisbon, Portugal (03/06)
2006–2007	Anita H. Clayton, MD, IF, FAPA	Lake Buena Vista, FL (02/07)
2007–2008	Annamaria Giralaldi, MD, PhD, IF	San Diego, CA (02/08)
2008–2009	Rosella E. Nappi, MD, PhD	Florence, Italy (02/09)
2009–2010	Sheryl A. Kingsberg, PhD, IF	St. Petersburg, FL (02/10)
2010–2011	Alan Altman, MD, IF	Scottsdale, AZ (02/11)
2011–2012	Alan Altman, MD, IF	Jerusalem, Israel (02/12)
2012–2013	Andrew T. Goldstein, MD, IF, FACOG	New Orleans, LA (02/13)
2013–2014	Andrew T. Goldstein, MD, IF, FACOG	San Diego, CA (02/14)
2014–2015	Sharon J. Parish, MD, IF, NCMP	Austin, TX (02/15)
2015–2016	Sharon J. Parish, MD, IF, NCMP	Charleston, SC (02/16)
2016–2017	Irwin Goldstein, MD, IF	Atlanta, GA (02/17)
2017–2018	Irwin Goldstein, MD, IF	San Diego, CA (02/18)

Association of Nurse Practitioners in Women's Health since 2014, providing educational content. The society has taught CME courses at the International Society for Sexual Medicine, American College of Obstetrics and Gynecology, and the International UroGynecology Association, providing evidence-based content to non-ISSWSH members and spreading awareness of women's sexual function and dysfunction.

In recent years, the society has moved into advocacy and has developed useful tools,

including publication of clinical pearls and assembling an official educational slide-set, both benefits for members. Online content for both providers and patients has been and will continue to be developed. Consensus panels have convened to establish clinical guidelines in different aspects of sexual dysfunction in women. ISSWSH is now established as a leading organization in disseminating valuable information to providers, researchers, and educators in order to improve management of distressing sexual dysfunction in women.

References

- 1 Goldstein I, Lue T, Padma-Nathan H, *et al.* Oral sildenafil in the treatment of erectile dysfunction. *New Engl J Med.* 1998;338:1396–1404.
- 2 Basson R, Berman J, Burnett A, *et al.* Report of the international consensus development conference on female sexual dysfunction: definitions and classifications. *J Urol.* 2000;163(3):888–893.
- 3 American Psychiatric Association. Diagnostic and Statistical Manual of Mental Disorders IV, Text Revision (DSM-IV-TR).

- American Psychiatric Association, Washington, DC. 2003.
- 4 Rossouw J, Anderson GL, Prentice RL, *et al.* Risks and benefits of estrogen plus progestin in healthy postmenopausal women: principal results from the Women's Health Initiative randomized controlled trial. *JAMA*. 2002;288(3):321–333.
 - 5 Bachmann G, Rosen R, Pinn VW, *et al.* Vulvodynia: a state-of-the-art consensus on definitions, diagnosis and management. *J Reprod Med*. 2006;51(6):447–456.
 - 6 Bornstein J, Goldstein AT, Stockdale CK, *et al.* 2015 ISSVD, ISSWSH, and IPPS Consensus Terminology and Classification of Persistent Vulvar Pain and Vulvodynia. *J Sex Med*. 2016;13(4):607–612.
 - 7 Portman D, Gass M, Kingsberg S, *et al.* Genitourinary syndrome of menopause: new terminology for vulvovaginal atrophy from the International Society for the Study of Women's Sexual Health and the North American Menopause Society. *Menopause*. 2014;21:1063–1068.
 - 8 Derogatis L, Sand M, Balon R, *et al.* Toward a more evidence-based nosology and nomenclature for female sexual dysfunctions – Part I. *J Sex Med*. 2016;13(12):1881–1887.
 - 9 Parish SJ, Goldstein AT, Goldstein SW, *et al.* Toward a More Evidence-Based Nosology and Nomenclature for Female Sexual Dysfunctions – Part II. *J Sex Med*. 2016;13(12):1888–1906.
 - 10 Reed GM, Drescher J, Krueger RB, *et al.* Disorders related to sexuality and gender identity in the ICD-11: Revising the ICD-10 classification based on current scientific evidence, best clinical practices, and human rights considerations. *World Psychiatry*. 2016;15(3):295–321.
 - 11 Goldstein I, Kim NN, Clayton AH, *et al.* Hypoactive sexual desire disorder: International Society for the Study of Women's Sexual Health (ISSWSH) Expert Consensus Panel Review. *Mayo Clin Proc*. 2017;92(1):114–128.
 - 12 Clayton A, Goldstein I, Kim NN, *et al.* The International Society for the Study of Women's Sexual Health Process of Care for Management of Hypoactive Sexual Desire Disorder in Women. *Mayo Clin Proc*. 2018;93.

