

ISSVD: The Past and the Future

Peter J. Lynch, MD
September 7, 2011

THE PAST

(with the help of presentations
made by Eduard Friedrich in 1983
and Guillermo di Paola in 2006)

ISSVD: The Past

- The idea of a vulvar disease society originated at the 1970 FIGO World Congress in New York City
- A six member organizing committee was created with Guillermo di Paola as Chair
- An inaugural session of what was to become the ISSVD was held at the 1971 ACOG meeting in San Francisco
- The founding document for the ISSVD, prepared by Eduard Friedrich was signed at that meeting by the 14 gynecologists who were present

The 14 Original Signers

- Vincent J. Capraro
- William C. Fetherston
- Ernest W. Franklin III
- Eduard G. Friedrich, Jr.
- Herman L. Gardner
- John R. G. Gosling
- Raymond H. Kaufman
- A. F. Lash
- George W. Morley
- Guillermo di Paola
- Harold M. Tovell
- J. Donald Woodruff
- V. Cecil Wright
- Kane Zelle

ISSVD: The Past

- During 1971 and 1972, approximately 20 additional physicians (including myself) were invited to join and be identified as Founding Fellows
- These included gynecologists, dermatologists and pathologists from various countries
- At this point the ISSVD became the first international, multi-specialty organization devoted to vulvar disease and the care of women with vulvar problems

ISSVD: The Past

- Guillermo di Paola was elected President and he presided over the 1st World Congress, held in Spain in 1973
- It was attended by 18 members and six guests
- Since then, 21 World Congresses have been held, in 14 different countries, at approximately 2 year intervals
- Total membership today is 326, (50% of whom are Active Fellows) representing 30 countries and multiple medical disciplines

ISSVD: The Past

- The Charter Document for the ISSVD, prepared by Eduard Friedrich in 1972, presciently contained the following three goals:
 - To provide interdisciplinary communication between gynecologists, pathologists, and dermatologists
 - To [promote] dialogue on an international basis to find and establish an agreement on the terminology of vulvar disease
 - To promote clinical investigation, basic research and dissemination of knowledge in this field
- These goals have guided us for 40 years and I expect they will continue to do so in the future

ISSVD: The Past

- As a member for 40 years, as one of four Founding Fellows still alive and active in the Society and, as an attendee at all but one of the Congresses, I have been a participant in the entire history of the ISSVD
- I suspect this longevity is what led to the invitation to speak to you today regarding the past and future of our remarkable Society
- I will review “the past” in relationship to the three goals previously mentioned demonstrating, I believe, that we have excelled in all three areas

First Goal: Communication

- Communication, our first goal, has been carried out through three approaches
 - Manuscript publication
 - Preparation of textbooks
 - Oral presentations and discussion at meetings
- The next few slides review what we've accomplished in each of these three communication approaches

First Goal: Communication

Manuscripts

- First, it is impossible to determine how many papers our members have published. But, based on my personal knowledge, it is certainly a thousand and likely many more
- To estimate the importance of our contributions, I scanned the most recent 200 papers on “vulvar disease” listed in PubMed. Our members have accounted for at least 8% of them
- In view of the huge number of gynecologists dermatologists, pathologists, etc., this is an extraordinarily high percentage for so few of us

First Goal: Communication

Textbooks

- Second, using several sources, I have identified approximately 30 textbooks that have an ISSVD member as one or more of the authors or editors
- This number does not count the multiple editions, or the translations, that have been published for many of these books
- Nor does it count the many chapters written by us for more general textbooks
- Our books make up the vast majority of all textbooks relating to the vulva and its diseases

First Goal: Communication

Verbal

- Third, postgraduate courses, for which our members were speakers, have been offered in association with all of our Congresses
- The vast majority of the numerous other vulvar CME courses annually offered throughout the world, have included our members as presenters
- I believe that our members represent the single most important source of vulvovaginal education throughout the last 40 years

Second Goal:

Terminology & Classification

- Our second goal was to provide terminology and classification for vulvovaginal disease
- Our recent publications in this regard include:
 - Vulvar pain: vulvodynia (2003)
 - Vulvar intraepithelial neoplasia (2004)
 - Vulvar dermatoses, pathological subsets (07)
 - Vulvar dermatoses, clinical (expected, 2011)
- These have been well respected and widely used

Third Goal:

Clinical and Basic Research

- As regards our third goal, In 2006, I made a partial list of our members who have provided new information in the areas of vulvovaginal malignancy, infections, dermatoses, vulvodynia, pediatric disease, histopathology, and normal appearance and function of the vulva.
- I have not brought this list up-to-date but, at that time, approximately 60 members had published new information in one or more of these areas
- Almost all of these represented clinical, rather than basic, research

ISSVD: The Past

- In addition to living up to our three major goals, we have had significant achievements in other areas such as:
 - Adding the “vagina’ as an area of interest and marked this by including “vulvovaginal disease in our name.
 - Creating a new type of membership to allow for inclusion of those whose major role falls primarily in the area of clinical care
 - Encouraging physician and non-physician membership from multiple disciplines outside of our original areas of gynecological, dermatological and histopathological specialties

THE FUTURE

(As one person sees it!)

ISSVD: The Future

- In the early years many predicted failure for our Society, believing that the medical world already had too many societies and that the field of vulvology was not important enough to warrant creation of a new society devoted solely to it
- But now, 40 years later, we not only exist but have grown in size and importance
- I am optimistic that we can continue to prosper but in the remainder of my presentation I will discuss several real or potential problems and several new challenging opportunities

Three Potential Problems

- 1) International vs. Regional Groups**
- 2) Relationships to Other Societies**
- 3) The “Elephant in the Room”**

1) International vs. Regional Groups

1) International vs. Regional Groups

- The original founders of our Society believed that there should be a single society that would represent all countries and all disciplines
- This concept has worked well for 40 years but may be less successful in the future
- Due, in part to the infrequency of our Congresses and the relatively high cost of attending them, multiple national and regional vulvar disease societies have been created
- This has many good aspects but there are downsides as well

1) International vs. Regional Groups (Cont.)

- These regional and national groups developed to increase the frequency of discussion, to avoid the high costs of attending international meetings and to encourage the development of local and regional cooperation for clinical studies
- These are excellent goals and I believe that these groups have been largely successful in achieving them
- Two different models have been used in the creation of these groups

1) International vs. Regional Groups (Cont.)

- In the **first model**, used by nearly all of the national and regional groups formed so far, development occurred almost totally independent of the ISSVD
- In the **second model**, used for the North American Chapter of the ISSVD, development took place with close financial and organizational ties to the ISSVD: the chapter must share profits from its CME courses and members must join the ISSVD within two years

1) International vs. Regional Groups (Cont.)

- Both models share a potential problem: that of shifting many of our previous ISSVD activities from an international to a local stage
- As this happens, we, as vulvologists, lose our current unified and powerful multispecialty and international position
- As local and regional activity increases, attendance at our World Congresses may decrease and the ISSVD may suffer financially

1) International vs. Regional Groups (Cont.)

- This seems appreciably less likely to happen when the second model of organization is used
- In fact, I worry that continued formation of organizations using the first model may leave the ISSVD as only an “umbrella” organization with essentially a single function, that of holding biennial World Congresses
- That would place us back where we were 40 years ago: weak and fragmented
- I urge currently existing groups to consider reorganization along the lines of the NA Chapter

2) Relationships to Other Societies

2) Relationship to Other Organizations

- Initially the entirety of vulvar disease was believed to be too small and unimportant to warrant the creation of a society for it alone
- We did it anyway and have been hugely successful
- But now we are seeing the rise of numerous subspecialties within vulvar disease such as oncology, colposcopy, laser therapy, cosmetic procedures, etc.

2) Relationship to Other Organizations (Cont.)

- As our members develop significant interest in these subspecialty areas, they will likely view the organizations related to them as increasingly more important to them than is the ISSVD
- This of course could weaken our Society both in importance and in financial viability
- For example, look at what has happened in America: as specialty societies have prospered, the former “powerhouse” organization, the American Medical Association (AMA), has steadily lost members and importance

2) Relationship to Other Organizations (Cont.)

- I see two potentially serious consequences of this subspecialty phenomenon
- **First**, subspecialty emphasis will undoubtedly lead to a decreased emphasis in “general vulvology” and a loss in the number “general vulvologists”...the very thing that primarily characterized our founding fathers
- While this would be a terrible thing for our patients, this risk appears to be greatly lessened because of the remarkably able assumption of this role by NPs and PAs

2) Relationship to Other Organizations (Cont.)

- **Second**, there is the possibility that these subspecialty organizations will become detrimentally competitive with us and our activities
- For example, I see this developing as the American Society for Colposcopy and Cervical Pathology (ASCCP) increases its interest in vulvar disease and vies with us for dates, sites and attendance at American CME vulvar disease courses

3) The “Elephant in the Room”

3) The “Elephant in the Room”

- Recently I have become aware of a concern among some of you that there is undue American influence in the administration and governance of the ISSVD
- I call this the “elephant in the room” because, probably to spare the feelings of Americans, it has not been discussed very openly
- Moreover, I recognize that there **is** a marked American influence, one based largely on the following seven considerations:

“Elephant in the Room” (Cont.)

- ✓ All but one of the original 15 signers of the Founding Document were American
- ✓ The Society was incorporated in the United States and must adhere to American business and tax rules
- ✓ Americans constitute the plurality of our membership: 45% of the members in 1981 and 43% today
- ✓ There are 141 American members. The country with the next largest contingent, the United Kingdom, has 30 members

“Elephant in the Room” (Cont.)

- ✓ Because of the size of its membership and the financial success of its CME courses, Americans contribute the single largest portion of our budget
- ✓ The ISSVD bylaws specify that the Treasurer be an American
- ✓ Our founders established the custom that the Secretary General and the Executive Director were to be American and that custom has remained in place for the last 40 years

“Elephant in the Room” (Cont.)

- I believe that this degree of American influence is not, and should not, be a troubling issue... though I recognize my bias in that regard
- There are two main reasons why I hold this view:
 - I believe that the ISSVD has run exceptionally well over the last 40 years with this model in place
 - I believe that, in spite of this “U.S. dominance”, there is ample opportunity for international input into ISSVD affairs since the six Councilors, the President, the President-Elect and the Past President may be from any country

Elephant in the Room” (Cont.)

- However, I realize that many other societies with international membership have different approaches to administration and governance
- And, it does not mean that I (and probably most American members) am opposed to change if that is the will of the majority of the members
- Thus, I suggest that an email survey be carried out and then, if the results warrant it, a new, seven person, international task force be charged to study the issue and make appropriate recommendations for change

Additional Challenges

Additional Challenges

- Is there any way we can attract those doing basic research to join, and become active, in the ISSVD?
- Is there any way to increase the number of intergroup cooperative studies so that uncommon diseases can be better examined?
- How can we increase the role of non-physician providers such as nurse practitioners, physical therapists, sex counselors, and psychologists?
- What can we do to increase mentoring for young, interested students and residents?

Additional Challenges

- How can our Society incorporate subspecialty interests more successfully?
- How can we reduce the costs of our World Congresses sufficiently such that all members who wish to do so, can afford to attend?
- How do we establish “vulvology” as a specific area in the curriculum of residency programs?
- Is it possible and/or desirable to establish vulvology as a “certified” fellowship?
- How do we create, and fund, electives in vulvology practices for students and residents?

Conclusions

Conclusions (1)

- First, for our organization to be considered successful by ourselves and by others, we must reaffirm that optimal care for women with vulvovaginal problems remains our single highest priority
- Second, for us to maintain our current, unified and powerful position, we must continue to invite transparent and frank discussion; it is the best way to prevent us from straying as we look to the future of our Society

Conclusions (2)

- In closing, I would like have you join me in celebrating the prescient foresight and magnificent accomplishments of the early “giants” who started this exceptional organization 40 years ago
- We all should be truly proud of them and the legacy they have created for us
- Let us commit to honor them by continuing to add to that legacy for the benefit of those who will follow us into the future