



**Minutes of the meeting of National Psycho-Oncology Societies  
27 April 2003**

**Banff Conference Center, Banff, Canada**

1. Call meeting to Order

Dr. Barry Bultz called the meeting to order at 9:15 AM. He welcomed the representatives from 24 countries, and stated the goal of this group to work together as a world community in psycho-oncology.

2. Website Initiatives

Mr. Jeremy Lundberg, IPOS webmaster, described the web-based initiatives. He described the plan to redesign the website in the coming weeks and months to include a members-only site, with all contact information and much more. He described the plan to translate the core units of the online curriculum into six different languages in web cast format, which shall be part of the IPOS Center for Education and Research. There is a plan to provide website pages for each national society on the IPOS site, which will include quarterly updates from each national society about issues and challenges in national arena. The website will also be updated to provide slides from the Sutherland lecture provided by Dr. Holland, along with pictures from this Banff Conference.

3. Introduction of Meeting Participants

Dr. David Kissane, Past President of IPOS, led the introductions and the participants from a number of nations provided information about the psycho-oncology programs, or needs for such programs, in their countries. A summary of reports from select countries follows.

**Brazil** has an active psycho-oncology society and is planning its 17<sup>th</sup> Annual meeting. It reports 4000+ cases of cancer per year, much of which would be treatable or available with education.

**France** reports membership in its society to be approximately 200. The theme for its Annual Congress is "Patient Education". It publishes a newsletter twice per year.

**Hong Kong** reports a Cancer Fund resource center for in-patient care. It provides peer support and counseling, rehabilitation education, information about fighting cancer and a

patient education program. There are 20-30 professionals in psycho-oncology, but no organized society.

**Hungary** reports its society was formed in 1988. Although it was troubled by poor participation, it has been renewed in 2002 with 80+ members. A significant philanthropic grant from the BMS Foundation is supporting an important 3-phase program.

**Iceland** has one cancer center and two hospitals with chemotherapy to support its population of 280,000. There is no organized society at this time, and approximately ten professionals are involved in psycho-oncology.

**India** reports that psycho-oncology is in its infancy stage. Two groups are working in the area. The first government funded psycho-oncology program came in 2002. Palliative care is in place, but physicians are not looking at quality of life through psycho-oncology support. There is a WHO collaborative center conducting research in India.

**Ireland** reports 21,000 cases of cancer per year, with few and fragmented psycho-oncology services. The field of psycho-oncology is acknowledged by the government and is now offered as a free service at two centers, and more are opening. There is no psycho-oncology society at this time.

**Italy** has a society of 300 members. The 2003 Conference is to be held in Sicily and is creating a network with southern European countries.

**Japan** reports 600 members in its national society and 3000 physicians in related fields.

**Jordan** reports that the King Hussein Cancer Center is the only cancer center in the country, but there are several peripheral locations offering chemotherapy. There is no psycho-oncology society, but a department of psycho-oncology is being created in the King Hussein Cancer Center.

**New Zealand** founded its first department of psycho-oncology in 2000 and they are working to develop interest and awareness. There are a few nurses and social workers involved in the area.

**Paraguay and Venezuela** report that there is no psycho-oncology society but there are plans to network with the programs in Brazil.

**Portugal** reports three oncology centers and a general hospital with oncology units. There are waiting lists for patients, but the care is good once a patient is seen and treated. The Academy of Psycho-Oncology was formed in 1999 and has about 100 members, although it is not very active. They bring speakers in from outside the country when they have meetings.

**Slovenia** has a palliative care institute. There are ten professionals in psycho-oncology, no national society, but a strong cancer society. There are approximately 20,000 cases of cancer diagnosed each year. There are plans developing to collaborate with nearby groups.

**Spain** reports a small but growing group of psycho-oncologists.

**Sweden** reports 40,000 cancer cases per year, treated in five centers and one rehabilitation center (plus several research groups) offering psycho-oncology services. There is no organized psycho-oncology society but there are 150 professionals in a national network that meets every odd year.

**Switzerland** reports 26 different healthcare systems in the country. There is a 60-member society and another society for palliative care. A practicing oncologist must have a certificate from a four-day training program in psycho-oncology.

#### 4. Summary of Basis and Impending Goals for IPOS

Dr. Christoffer Johansen, President of IPOS, made a presentation that summarized the basis of and future plans for IPOS and the national Societies. He reiterated that the mission of IPOS is to foster international multidisciplinary communication about clinical, educational and research issues that relate to the subspecialty of psycho-oncology and two primary psychosocial dimensions of cancer: 1. response of patients, families and staff to cancer and its treatment at all stages; and 2. psychological, social and behavioural factors that influence tumour progression and survival. He described the membership as being multidisciplinary, including physicians, social workers, nurses, psychologists, rehabilitation specialists, epidemiologists, social scientists and educators from around the world.

Dr. Johansen described the activities of IPOS scheduled for implementation in the near future (2003-5).

- Organization and sponsorship of at least biennial scientific world conferences, in collaboration with national or regional psychosocial organizations. There is a significant process in the undertaking to become a non-governmental organisation (NGO) of the World Health Organization (WHO) in order to become a partner in the ongoing policy development within WHO as it impacts the prevention and treatment of cancer. The focus of the NGO activities is directed towards the definition and establishment of worldwide clinical guidelines for psychosocial support for cancer patients. IPOS is also making plans to conduct a world congress to establish clinical guidelines.
- The establishment of educational activities in collaboration with the European School of Oncology (ESO) in Milan, Italy in relation to clinical oncologists and

researchers in psychosocial oncology. This program will take place at the 7<sup>th</sup> World Congress in August 2004, Copenhagen, Denmark.

- Establishment of and IPOS Centre for Education and Research (ICER), which will serve as an umbrella Centre, including a project to translate Core Curriculum into multiple languages, and will include identification of a Faculty of Senior Teachers to be available for plenary speaking to meetings of National Societies.
- Active participation in initiatives taken by the International Agency for Research on Cancer (IARC), the cancer research institute of WHO and the collaboration between The International Union Against Cancer (UICC) and WHO.
- Further support for and development of the *Journal of Psycho-Oncology*, which serves as the scientific journal focused on psychosocial oncology in all aspects (2002 impact factor 1.388).
- Establishment of an Office of National Societies, with Dr. Jimmie Holland at Memorial Sloan Kettering Cancer Center, prepared to help new National Societies in establishing psychosocial oncology in the country or region.
- Establish the necessary financial stability for the existence of IPOS.
- To establish a clear strategy to promote collaboration between IPOS and psychosocial societies in the emerging world.

At this time in the meeting, the floor was opened for general comments and discussion.

1. Consider the value of standards/guidelines for policy makers; CAPO has a set of standards on its website. Dr. Holland commented on the need to determine the standard and then develop guideline. IPOS should adopt the goal to develop a worldwide benchmark that can then be modified for cultural differences. This would be a good basis for supporting the WHO NGO application and an appropriate task on which to focus at the 7<sup>th</sup> World Congress in Copenhagen. IUCC has recognized the value of disciplines that comprise psycho-oncology. We should ask IUCC to refocus from just a biological orientation. IPOS must represent the stakeholders, not just the professionals, including survivors and advocacy groups. There is a basic need for more methodology (which tool to use and when; how to compare results). This would be a good topic for a workshop in advance of the Copenhagen Congress. Epidemiology research should be an additional focus in the ICER. Dr. Holland shared her vision for a core of instruments to compare across countries. With solid funding and influence the regulators will have to listen.
2. Palliative medicine seems to be stronger than psycho-oncology. We should consider forming alliance with palliative medicine and seek ways to attract individuals to this field. In order for this to work, more must join IPOS. The Journal is good. Perhaps IPOS members could choose between hard copy, e-access or no subscription to the

- journal. IPOS also will draft a hardship policy for those that are unable to pay dues. CAPO does not require journal. IPOS's goal is to increase awareness and network. Dr. Koch will speak to Dr. Edelstein about an optional subscription policy for IPOS members.
3. There is no difference in meaning between psychosocial oncology and psycho-oncology. The terms may be used interchangeably.
  4. The IPOS Board shall consider a request to post the screening tools on the website. Online, IPOS could provide references for scales that could be used for screening.
  5. The WHO/NGO application process timeline is undetermined. We are developing the structure to convince WHO to assess our viability, and it is likely to be a several year process, but it is being initiated. When NGO status is attained, WHO could be a source of funding to establish programs in underdeveloped nations.
  6. It is important and valuable to think about forming some key working parties in the near future, e.g. Research Committee and Education Committee, to continue generating the momentum that is beginning in Banff. It was agreed that POS may not be completely established for this level of commitment, but the Board shall begin with bimonthly conference calls and will post its minutes to the web for access by all members. The Board also intends to meet face-to-face at least once or twice per year. Headquarters will send notice on the list serve to members when minutes posted.
  7. For global representation, the Copenhagen Program Committee desires that a representative from each National Society shall chair a session at the 7<sup>th</sup> World Congress.
  8. Anyone interested in chairing or serving on the IPOS Education Committee, please contact Headquarters at [info@ipos-society.org](mailto:info@ipos-society.org).
  9. Anyone interested in working on the project to develop clinical care guidelines should contact Dr. Holland at [hollandj@mskcc.org](mailto:hollandj@mskcc.org).
  10. IPOS believes in the importance of addressing the needs of under-resourced nations. The previous Soviet Union (eastern Europe) is also in great need for psychosocial oncology support: Ukraine, Georgia, Armenia, Poland, Russia. They have more support in area of palliative care, but not so much for psychosocial oncology care. IPOS is willing to educate physicians and collaborate. The Dr. - Patient relationship is very poor in the identified countries; patients are not even told of their diagnosis. Dr. Holland reported on a meeting scheduled for Ghana in 10/03 (AORTIC) for which she is developing the psycho-oncology piece and is looking for assistance in establishing this program. Psycho-oncology shall be part of palliative care. Anyone interested in providing support for this meeting should contact Dr. Holland. IPOS is an appropriate umbrella for this service. Core online curriculum in multiple languages will be helpful here. A Russian

language would be good as well. Countries represented here should provide IPOS with contacts for translation.

11. An idea was set forth to urge people to join IPOS as part of their curriculum or as part of multicenter trials.
12. The participants requested distribution of the Congress attendance list to continue communication and networking. It was agreed that CAPO would create a database of all the Congress participants and distribute a link to the database by e-mail.
13. There seems to be generally adequate funding for Palliative Care. One approach to obtaining additional support and funding is to link psycho-oncology to palliative care for grant requests and developed psycho-oncology from there.
14. The PowerPoint presentation for the Hungarian case study shall be posted to the IPOS website.