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*Welcome to the January edition of the ISOO Newsletter. Do you have an article or news that you would like to share? Please contact Allan, AHovan@bccancer.bc.ca or Tanya, trouleau@hsnsudbury.ca
Dr. Allan Hovan and Dr. Tanya Rouleau (Co-Editors, ISOO Newsletter)*

President's Message

As 2014 draws to a close it's a good time to reflect on the year and think about what 2015 might bring.

This has been a busy year for ISOO and in some respects a year of change – particularly with respect to our new membership fee, which was introduced following the new Memorandum of Understanding signed with MASCC in Berlin in 2013. I know that there were concerns at the time that this might result in a reduced membership and have some other negative aspects. Fortunately, at the time of writing, the ISOO membership, although not huge, is still quite strong – comprising approximately 30% of the general MASCC membership. There were various reasons for bringing in this fee, for example it was considered that having a (very) modest income would enable the ISOO to do things such as facilitate the development of new projects as well as be used to help promote the ISOO and its mission to improve oral (and general) health for cancer patients more widely. It was also considered important that we know that the members we have really want to be part of the ISOO – this was something I was not too concerned about – it is clear that the ISOO members have very clear goals and are highly motivated in their various clinical areas related to oral oncology.

With respect to the size of our membership, whilst browsing through past ISOO newsletters recently, I came across Judith Raber-Durlacher's President's report from 2003 (I don't even think I was an ISOO member then, from memory I was just considering having a chat with Dorothy Keefe about starting a PhD – what a lot has changed since then!). In her report, Judi asked what difference a small group of idealistic members can make. Judi thought that the ISOO was on the right path back then and that the multidisciplinary interactions within the ISOO and with MASCC members create many important opportunities. I think that 11 years down the track Judi's comments are still valid. The amount of work that members of the ISOO do is considerable, for example: developing consensus papers, oral care guidelines, and systematic reviews; and as a result the ISOO does make an impact. This was also confirmed by the feedback received from the ISOO session at this year's MASCC/ISOO meeting in Miami – the rating for our sessions was generally high – a small group therefore can provide a valuable contribution.

Having said that however, I think it is really important that we continue to encourage our colleagues to become members of the ISOO, by growing our membership we create broader opportunities for collaborative research, better patient education and care, as well as broader recognition of the importance of oral care for cancer patients and its impact on their general health.

For 2015 I look forward to continuing the excellent work that the ISOO does through the efforts of its members. Many important projects are continuing and there are opportunities to collaborate with other organisations that have similar or complementary goals to the ISOO – these are really exciting. An excellent program has been put together for this year's meeting in Copenhagen, and I encourage you all to attend if possible, where I look forward to seeing you.

Richard Logan, Australia
ISOO President



Assessing Quality of Life in Cancer Patients

The essence of supportive and palliative care is to improve patients' quality of life (QoL). Unfortunately, QoL measurements are underused as endpoints in clinical studies and are not implemented well enough in our daily clinical work. This is partially because of a lack of specific tools to measure oral health related QoL in cancer patients. Such a tool, the EORTC H&N35 quality of life questionnaire (QLQ), has been in clinical use for many years, however, it is relevant only for head and neck cancer patients. Moreover, it was developed more than 20 years ago, long before the introduction of IMRT, chemoradiation and targeted therapies.

Over the past 30 years, the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Group (QLG) has developed numerous self-reported questionnaires to assess QoL in oncology. These tools generally use a modular approach, with a 30-item core questionnaire (EORTC QLQ-C30) and additional modules for different cancer sites, treatment side-effects, or functional problems.



Currently, there are 2 projects ongoing within the EORTC QLG that might be of interest for ISOO members: the development of a specific QLQ for assessing oral health related QoL in all cancer patients (EORTC OH17) and a revision of the "old and good" H&N QLQ (now called EORTC H&N43) to address the new treatment regimens IMRT, chemoradiation and targeted therapies. These two questionnaires are the fruits of a joint effort of a multidisciplinary group composed of psychologists, physicians, surgeons and dentists, some of them are also ISOO members (Bente Brokstad Herlofson, Judith Raber Durlacher, Ourania Nicolatou-Galitis, Noam Yarom). The questionnaires were translated and validated in many languages and will be soon available via the EORTC QLG website (<http://groups.eortc.be/qol/>), free of charge for academic studies.

Noam Yarom, Israel
Susanne Singer, Germany



In Remembrance of Dr. Michele Williams

It is with great sadness that we inform you of the passing of Dr. Michele Williams on January 8th, 2015 after a one-year battle with cancer. Michele was an active member of MASCC/ISOO and the Oral Care Study Group. She had most recently been involved with the systematic reviews and served as the Canadian lead on the OraStem study.

Michele received her BSc (Nursing) degree from the University of British Columbia (UBC) and worked for 10 years as an oncology nurse before returning to UBC to complete her undergraduate dental degree. She then went on to complete a Certificate in Oral Medicine at the University of Pennsylvania (Philadelphia). She was a Diplomate of the American Academy of Oral Medicine and a certified specialist in Oral Medicine with the College of Dental Surgeons of British Columbia. Since graduation, Michele had maintained an active referral practice in Oral Medicine.

At the time of her death, Michele was the Oral Medicine practice leader in the Program in Oral Medicine/Dentistry at the British Columbia Cancer Agency and the Acting Head of the Department of Dentistry at Vancouver General Hospital. Throughout her career, Michele had received numerous awards recognizing her contributions to the profession of dentistry. Her particular passion was care for patients with oral cancer and hematologic disease. A memorial award is being established in her name at UBC. This award will be given to a student demonstrating excellence in Oral Medicine.

Diagnostic and Management Practices for Oral Chronic Graft-Versus-Host Disease (cGVHD)

The Oral Care Study Group conducted a study on the diagnosis and treatment of oral chronic graft-versus-host disease (cGVHD). The study was designed to assess common practices, as well as to determine use of the National Institute of Health scale for the diagnosis and grading of oral cGVHD. The project was headed by Sharon Elad, DMD, MSc, Eastman Institute for Oral Health, University of Rochester Medical Center.

A survey was distributed to Oral Care Study Group and MASCC/ISOO members in order to identify medical centers with experience in managing patients with oral cGVHD. The structured survey contained questions about the respondents' demographics, whether or not they treat oral cGVHD, evaluation tools, diagnostic aids, topical treatments, and preventive measures. Seventeen MASCC/ISOO members responded to the survey, 12 of whom reported that they treat oral cGVHD patients on a regular basis. Of these 12, 6 practice in the US, and 6 practice in Europe. Eleven of the 12 are dentists.

Of these 12 respondents, 75% did not use biopsy to diagnose oral cGVHD. This is consistent with NIH guidelines, which consider clinical observation of oral lesions sufficient for diagnosing oral cGVHD. The first-line topical treatment for oral mucosal cGVHD was predominantly steroids (91.7 %), and the second preferred topical treatment was tacrolimus (41.7 %). The preferred treatment for hyposalivation was systemic pilocarpine (41.7 %). Most practitioners recommend regular topical fluoride use for prevention of dental caries and most recommend an oral cancer screening protocol. While the recommended frequency varied, 50% suggested a follow-up every 6 months.

This study also sought to assess the level of implementation of existing cGVHD diagnostic and assessment tools. The results showed that 42% of represented sites have adopted the NIH guideline approach for diagnosis of oral cGVHD. Most clinics used a standard tool for evaluating symptoms, but not for evaluating clinical signs of oral cGVHD. The NIH scale for grading response was not used routinely by most responders. The use of standard assessment tools would facilitate data collection across medical centers, thereby allowing for conclusions regarding optimal management.

Although the number of respondents was small, the study provides a snapshot of current practice among a specialized group of professionals with expertise in this disease. The study highlights the importance of standardizing assessment methods across clinics, which would enable standard data collection, thereby allowing for conclusions regarding optimal diagnosis and management of oral cGVHD.

For full results of the study, see: Elad S, Jensen SB, Raber-Durlacher JE, Mouradian N, Correa EM, Schubert MM, Blijlevens NM, Epstein JB, Saunders DP, Waltimo T, Yarom N, Zadik Y, Brennan MT. Clinical approach in the management of oral chronic graft-versus-host disease (cGVHD) in a series of specialized medical centers. *Supportive Care Cancer*, 2014 Nov 23. [Epub ahead of print]

The authors would like to acknowledge the support of the Oral Care Study Group and its Chair, Dr. Siri Beier Jensen, DDS, PhD, and also thank the members who participated in this study.

Sharon Elad, USA

Upcoming Meetings of Interest

2015

[ICHNO 2015 – International Conference on Innovative Approaches in Head and Neck Oncology](#)

Nice, France, 12-14 February 2015

[American Academy of Oral Medicine/American Academy of Oral and Maxillofacial Pathology](#)

San Diego, California, 18-24 April 2015

[American Head and Neck Society—Translational Research Meeting and Annual Meeting](#)

Boston, Massachusetts, 21-23 April 2015

[3rd Congress of European ORL-HNS](#)

Prague, Czech Republic, 7-11 June 2015

[MASCC/ISOO Annual Meeting on Supportive Care in Cancer](#)

Copenhagen, Denmark, 25-27 June 2015

[5th World Congress of the International Academy of Oral Oncology](#)

Sao Paulo, Brazil, 8-11 July 2015

[World Congress on Larynx Cancer](#)

Cairns, Queensland, Australia, 26-30 July 2015



MASCC/ISOO Annual Meeting • Copenhagen 2015

Abstract Deadline: **February 15, 2015**

Submit your abstract today!

Early Registration Deadline: **April 24, 2015**

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