Welcome to the April Issue of the MASCC Society News

Message from the Editor, Toni Clark

This month, we bring you a profile of the Mucositis Study Group, highlights of the recent member survey on MASCC benefits and services, and we announce some new books on supportive care in cancer. April is Global Testicular Awareness Month and in recognition, we review some recent research on supportive care for testicular cancer survivors. This month we welcome 11 new members who joined us in January.

As always, you can find the current and older issues of the MASCC Society News online at www.mascc.org/newsletters or in the back pages of our journal, Supportive Care in Cancer.

PROFILE: The Mucositis Study Group

The Mucositis Study Group (MSG) was established with the goal of improving outcomes of patients with oral and gastrointestinal mucositis resulting from anticancer therapies. The MSG represents both MASCC and ISOO and comprises more than 250 members committed to reducing the burden of mucositis through research, education, policy, and effective programs. Members include clinicians, researchers, and other interested professionals from around the world.

The recognition that mucositis is one of the most debilitating complications of cancer therapy motivated MSG members to collaborate on the development of evidence-based clinical practice guidelines for managing mucositis. Other objectives of the MSG include the following:

- To promote high-quality research for mucositis
- To disseminate up-to-date educational information about mucositis
- To serve as a resource for investigators in basic science, clinical, and health services research, as well as for industry collaborators, clinicians, and patients

Clinical Practice Guidelines. Since the early 2000s, the MSG has worked toward the development of evidence-based clinical guidelines, with the first publication in 2004, an update in 2007, and a third edition in 2014. Many other publications have detailed the process and conclusions reached during guideline development, and many MSG members participated in the research, writing, publication, and dissemination. The guidelines are now included in the US National Guideline Clearinghouse™ (NGC), a database of evidence-based clinical practice guidelines maintained by the US Agency for Healthcare Research and Quality (AHRQ), Dept. of Health and Human Services. They have been cited extensively and referenced by major societies in the field of oncology, such as European Society of Medical Oncology (ESMO) and the National Comprehensive Cancer Network (NCCN). The guidelines have been translated into several languages, including Italian, Japanese, Greek, and French. Chinese, Portuguese and Turkish versions will be available soon. For more information, see www.mascc.org/mucositis-guidelines.

Mucositis Research Workshop. The MSG held its first Mucositis Research Workshop during the 2007 MASCC/ISOO conference in St. Gallen, Switzerland. Its success led to the decision to hold an annual workshop, and a few years later, it became fully integrated into the MASCC/ISOO Annual Meeting. The ninth Mucositis Research Workshop, to be held at the 2016 meeting in Adelaide, will include a rich scientific program of original cutting-edge research and will feature an expert panel of world leaders in the field of mucositis. The Mucositis Research Workshops also provides an opportunity for MSG members to reunite with colleagues and make new friends as well. It provides a perfect atmosphere for exchanging information and opinions about recent advances and future research directions.

Ongoing and Current Projects. Projects for the coming months include continued dissemination of the Mucositis Practice Guidelines, additional translations, development of a patient-friendly version of the guidelines, and a review of measurement scales for mucositis in collaboration with the Oral Care Study Group. The patient-friendly guidelines will feature the essential information in the original guidelines, but in language more suited to a nonmedical audience. This will be helpful for patients and for healthcare providers who often need educational materials to share with patients. For information about future projects, watch for MSG emails and updates on the Study Group’s web page.
The Mucositis Study Group, continued.

Members and Membership. The MSG members are the key reason for the success of this group. Their shared interest, high motivation, and collaborative efforts provide the energy that drives the MSG and has led to its achievements. The Study Group leaders wish to express their appreciation to all the group’s members and encourage continued enthusiasm and spirit. Chair Sharon Elad also invites new professionals to join this productive Study Group. (See membership information at the MASCC website.)

Past and Present Leadership. The MSG was formed in 1998 and was co-led in its early years by Edward Rubenstein, Mark Schubert, and Douglas Peterson, who also led in the development of MASCC’s first clinical guidelines for the prevention and treatment of cancer therapy-induced oral and gastrointestinal mucositis. The subsequent Chair was Dorothy Keefe, who was succeeded by Rajesh Lalla. As of June 2015, the Chair is Sharon Elad. The Vice-Chairs are Paolo Bossi and Karis Cheng.

Sharon Elad, DMD, MSc, holds dual appointments as Professor of Dentistry and Professor of Oncology at the University of Rochester, where she is Chair of the Division of Oral Medicine at the Eastman Institute for Oral Health. Sharon is also the Clinical Chief for Hospital General Dentistry at Strong Memorial Hospital in Rochester. Her main research interests are in oral medicine, oncology, hematology, and special care dentistry. Sharon has led several international clinical trials, primarily on oral graft versus host disease. She served as General Secretary of the ISOO from 2005 to 2013 and as Chair of the Israeli Society of Oral Medicine from 2002 to 2010. She has published extensively in the professional literature, has edited several book chapters, currently serves on the Editorial Boards of *Oral Oncology* and *Quintessence International*, and is a member of the American Academy of Oral Medicine.

Paolo Bossi, MD, is a medical oncologist at the Fondazione IRCCS Istituto Nazionale dei Tumori, in Milan, Italy. Paolo is one of the founders of NICSO, the Italian Network of Supportive Care in Cancer and is member of ESMO and of the EORTC Head and Neck Cancer group. An expert in head and neck cancer and in adverse effects of chemo-radiation and targeted agents, Paolo is the author or co-author of numerous research papers on the prevention and treatment of oral and gastrointestinal mucositis following such therapies, as well as acute skin toxicity, nausea, vomiting, and dysphagia. Current research projects include head and neck cancer studies from translational research (gene expression, next generation sequencing) to assessment of quality of life and value-based medicine.

Karis Cheng, RN, PhD, FHKAN, is a Professor at the Alice Lee Centre for Nursing Studies, National University of Singapore and Honorary Professor, Faculty of Health and Social Care, University of Hull, UK. A pioneer in the field of mucositis in pediatric cancer patients, Karis has published widely in the areas of cancer therapy-related mucositis and symptom management, quality of life, survivorship care, and psychometric evaluation. Her work includes one of the first papers on the oral care of pediatric patients receiving cancer therapy and one of the first instruments on quality-of-life measurement among adults treated with chemotherapy, head/neck, or high-dose chemotherapy for hematopoietic stem cell transplant. Karis served on the Board of Directors of ISOO from 2011 to 2013. Currently, she serves on the Leadership and Governance Committee of SIOG’s Nursing and Allied Health Interest Group. She is also an Associate Editor of the *International Journal of Qualitative Methodology* and serves on various editorial and peer review boards of international refereed journals.


Use of MASCC Services and Benefits

Last fall, the MASCC Membership Committee surveyed members on their use of, and preferences for, various MASCC services and member benefits. The survey was undertaken so that the Society can better meet the needs of all members.

Of about 1,000 MASCC members, nearly 30% responded. Almost half of these were physicians (oncologists, palliative care physicians, and others), followed by nurses, dentists and oral surgeons, pharmacists, and psychologists. Other professions included physiotherapists, social workers, and trainees. Most respondents live and practice in Europe or North America, though Asia and Australia were also well represented. While many members are very active in the organization (e.g., through study group participation), more than 40% said they would like to be more involved in MASCC.

Respondents were asked to indicate their level of satisfaction with several MASCC services and activities: journal subscription, study group membership and involvement, the website, member access to virtual symposia and to the membership directory, and conference registration discounts. In general, most respondents were either “satisfied” or “very satisfied” with these benefits, with subscription to Supportive Care in Cancer having the highest number of “very satisfied” respondents. Other benefits most valued by members were the annual meeting, clinical guidelines, study group membership, and the opportunities for professional networking.

Nearly 70% of the respondents said that they visit the MASCC website at least once a month, and more than 18% do so once a week or more. Members most often visit the site to access MASCC guidelines and tools, the journal, study group pages, and this newsletter. Respondents were more likely to read the Society News on the website than in the back of our journal. In August of last year, we began emailing a link to the online edition of the Society News to all members on the first of each month. Nearly 60% of survey respondents said that they had read most or all of the newsletters since they started receiving these emails. Moreover, there was a high preference for the online edition (almost 80%) over the print version.

The survey also allowed respondents to indicate any additional information they would like to find on the MASCC website. Here are a few of the most common responses:

- Listings of local, regional, and international meetings related to supportive care in cancer
- More information about study groups and their ongoing projects
- Ways to become more involved in MASCC activities
- Other resources (books, videos, educational materials)
- Ways to network and collaborate with colleagues
- Job opportunities

Many respondents said that they are satisfied with the website and feel that it offers useful content. We are happy to hear this. We will continue to try to meet members’ needs and to post more information of interest. Also, we encourage study group leaders to let us know about group activities and ways that members can become involved, so that we can make the information available to all MASCC members.

Membership Committee Chair Alex Chan said that the survey results are very encouraging and confirm that the Society is providing services on par with our members’ needs and expectations. He added that, “the Membership Committee is always on the lookout for new ideas from our members and we invite you to join the Committee meeting in Adelaide. This is a good way to become more involved with MASCC!”

NEW BOOKS on Supportive Care

Check the Supportive Care Books page at the MASCC website to see the latest titles. Many are available to MASCC members at a substantial discount.

Recent and Forthcoming Books by MASCC Members

The MD Anderson Supportive and Palliative Care Handbook. Edited by Eduardo Bruera and Shalini Dalal. Fifth Edition. 2015. The fifth edition of the Handbook was conceived as a practical bedside tool to assist clinicians in the daily care of patients. This new edition reflects recently acquired knowledge on the assessment of major physical and psychosocial symptoms, as well as new pharmacological and nonpharmacological interventions for supportive and palliative care adopted by the Center’s Department of Palliative, Rehabilitation and Integrative Medicine. To order, contact Deanna Cuello at 713-794-1887 or dcuello@mdanderson.org.

Cancer-Related Fatigue. By Joachim Weis and Markus Horneber. 2015th Edition. Springer Healthcare. Cancer-related fatigue is widely recognized as a significant problem for patients with cancer and for those in remission. Weis and Horneber’s Cancer-Related Fatigue provides a concise overview of this condition, with an evidence-based discussion of diagnosis, treatment, and long-term management. The authors consider both pharmacological and nonpharmacological approaches, including psychosocial, mind-body interventions, exercise therapy.
Oxford American Handbook of Hospice and Palliative Medicine and Supportive Care (Oxford American Handbooks in Medicine) 2nd Edition. Edited by Sriram Yennurajalingam and Eduardo Bruera. Oxford University Press. The Oxford American Handbook of Hospice and Palliative Medicine and Supportive Care is an easy-to-use resource for the day-to-day management of patients who need palliative and hospice care. The contents follow the core curriculum of the American Board of Hospice and Palliative Medicine and is designed to meet the educational and clinical information needs of students, residents, fellows, and nurse practitioners. The 2016 edition has been updated to incorporate the National Consensus Project for Quality Palliative Care Clinical Practice Guidelines. It also contains new sections on grief and bereavement, medical marijuana, and physician assisted suicide.

Paperback Release:


Supportive Care for Testicular Cancer Survivors

In the past few months, several studies have explored the ongoing symptoms, health-related quality of life, and supportive care needs of testicular cancer survivors. The fact that this cancer often occurs in adolescents and young men has particular implications for their supportive care.

Testicular cancer patients face many struggles in the transition to post-treatment survivorship. Psychological distress, often related to fear of recurrence, is common. Many survivors develop long-term chronic fatigue, which has been linked to neuropathy and to lower testosterone levels, and which is often perceived as highly distressing. Also, lower cognitive performance and white matter changes have been reported in testicular cancer survivors 10 years after chemotherapy.

There is some indication that the greatest needs occur soon after treatment ends. Younger age at diagnosis and shorter time since diagnosis have been associated with higher levels of anxiety and depression among testicular cancer survivors, despite their having a good prognosis. Men who have children and those with more physical symptoms have also been found more likely to experience psychological distress. However, Hartung et al. found that long-term quality of life of germ cell tumor survivors was similar to that of other men of their age.

Recently, a research team including MASCC members Ian Olver and Martin Stockler reported on the prevalence, severity, and correlates of psychological distress and impaired health-related quality of life after treatment for testicular cancer. They found that most survivors experience only mild psychological distress and health-related quality-of-life impairments. However, for a subset of more vulnerable patients, the sequelae are more severe. The greatest problem affecting quality of life was fear of recurrence. The research team reported that the strongest correlates of psychological distress and impaired quality of life were feelings of helplessness, inadequate coping, and a lack of social support. The same research group had earlier found that a majority of testicular cancer survivors, especially those of younger age, reported unmet needs relating to survivorship issues.
supportive care continued… The high survival rate of testicular cancer patients makes long-term monitoring especially important. Shen et al. have recommended that supportive care for these men should move away from a disease-centered approach and toward a wellness-centered approach. Smith et al. observe that, since the perception of unmet needs is associated with psychological distress and lower health-related quality of life, future interventions should address this constellation of issues. And Sprauten et al. have suggested that lifestyle interventions, early detection and treatment of depression and anxiety, and possibly testosterone substitution, might reduce the risk of chronic fatigue.

Need a MASCC Member Certificate?
Log in to your account at the MASCC/ISOO website. On the member landing page, you'll see a link to download a membership certificate. This will download to your computer a Certificate of Membership (pdf file) with the MASCC logo, your name and member ID, your next membership renewal date, and the date of issue. The certificate carries the signature of Executive Director, Age Schultz.

MASCC Membership Benefits
MASCC membership entitles you to many benefits: access to the online edition of our official journal, Supportive Care in Cancer; our Member Directory (easy to search using multiple criteria); discounts on books about supportive care; membership in up to three Study Groups; discounted registration for our Annual Meeting; and contact with researchers and clinicians around the world who share your commitment to supportive care in cancer.

New MASCC Members
MASCC welcomes the following new members who joined us in January:
Samuel Idowu Ayeni, Nigeria
Tetsuhito Konishi, Japan
Daisuke Naruge, Japan
Enio Pestana, Portugal
Benjamin Schultze, United States
Inger Utne, Norway
Uday Venkat Mateti, India
Danica Vidovic Juras, Croatia
Anne Wilkinson, Australia
Hadi Zamanian, Islamic Republic of Iran
Aldo Zuliani, France

Have any news items to share?
Please send contributions for the MASCC News to MASCCnews@mascc.org or to Tomi Clark, Editor at tclark@mascc.org.

For more information please contact: Age Schultz, MASCC Executive Director: aschultz@mascc.org