Welcome to the December Issue of the Society News

Message from the Editor, Toni Clark

This month, we are pleased to announce the induction of MASCC member Sandra Mitchell as a Fellow in the American Academy of Nursing. We announce the 2016 pre-conference workshops, bring you news from the European Cancer Congress and profile MASCC’s Education Study Group. As this month’s research feature, we highlight two recent studies about patient-reported adverse effects of anticancer treatment. This month we welcome 12 new members who joined us in September.

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.

Sandra Mitchell Inducted as a Fellow in the American Academy of Nursing

MASCC member Sandra Mitchell, PhD, CRNP, AOCN, was one of nine members of the Oncology Nursing Society who were inducted as Fellows of the American Academy of Nursing in October, 2015. The induction took place at the Academy’s annual policy conference in Washington DC. Margaret Barton-Burke, PhD, RN, FAAN, President of the Oncology Nursing Society, praised the inductees for their contributions to improving care delivery and outcomes for individuals with cancer and their families. Fellows are selected on the basis of their leadership contributions to nursing and healthcare, in particular the extent to which their careers have influenced health policy, as well as the health and wellbeing of patients.

Sandra Mitchell is a research scientist in the Outcomes Research Branch at the US National Cancer Institute. Her areas of research include measurement of symptom burden, physical function, fatigue, and comorbidity across the cancer continuum. She has extensive experience in the analysis and interpretation of patient-generated health outcomes data. She is the Science Officer for the development and testing of the National Cancer Institute’s Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE), the subject of a recent article in JAMA Oncology, of which she is co-author. Sandra is a member of three MASCC Study Groups: Fatigue, Geriatrics, and Rehabilitation, Survivorship, and Quality of Life.

MASCC at the European Cancer Congress in Vienna

The European Cancer Congress 2015 was held in Vienna, Austria, from September 25 to 29, with a theme of “Reinforcing Multidisciplinarity.” This is a biennial meeting with the aims of improved prevention, diagnosis, treatment, and care of cancer patients. With its many organizational partners, the ECC represents a truly multidisciplinary approach to cancer treatment and care. The Congress featured several scientific and poster sessions on supportive care and palliation, including an ECC-MASCC Joint Session, with numerous presentations by MASCC members and other international experts. MASCC also had a booth at this year’s meeting, where Executive Director Åge Schultz shared information about MASCC and, in particular, the forthcoming MASCC/ISOO meeting in Adelaide, Australia, in June, 2016. You can find coverage of this year’s Congress with reports of the latest research, trials, and scientific advances by going to Conference Insider at http://www.cancernetwork.com.
2016 Pre-Conference Study Group Workshops Announced

The 2016 MASCC/ISOO Annual Meeting in Adelaide, Australia (June 23-25) will feature six Pre-Conference Workshops. The workshops are offered by Study Groups and held on Thursday morning before the Meeting’s Opening Ceremonies. They provide an opportunity for Study Group members to focus on a topic in depth, to share research knowledge, and to explore potential collaborations. The following workshops were selected by the MASCC Executive Committee from a pool of 10 applications.

**Mucositis Research.** The Mucositis Study Group will offer a workshop centered on the presentation of original research, both pre-clinical and clinical, by both beginning and experienced investigators. The workshop will provide information about the latest research advances, an informal venue for detailed discussion, and a means of identifying new opportunities for research and collaboration. The workshop will be led by Sharon Elad, MD, Chair of the Mucositis Study Group, along with Vice-Chairs Paolo Bossi, MD, and Karis Cheng, MD.

**Sleep, Drowsiness, and Fatigue in Cancer Patients.** Insomnia and other sleep problems are among the most prevalent and distressing problems reported by cancer patients, and they are often related to fatigue. They may affect ability to tolerate treatment and subsequent survival. Yet such sleep problems are often underdiagnosed and undertreated in this population. This workshop, co-sponsored by three Study Groups, will focus on sleep disturbances in cancer patients, including diagnosis and management. Diwakar Balachandran, MD, and Oxana Palesh, PhD, will lead the workshop. The following Study Group leaders are also involved: Karen Mustian, MD, Chair; David Hui, MD, Chair; Palliative; Irma Verdonck-de-Leenuw, Chair, Rehabilitation, Survivorship, and Quality of Life.

**Supportive Care for Patients Undergoing Immunotherapy.** Bernardo Rapoport, MD, will lead this workshop co-sponsored by three Study Groups: Oral Care, Skin Toxicities, and Neutropenia, Infection, and Myelosuppression. The workshop will focus on the new class of therapeutic agents known as immune checkpoint inhibitors, which play an important role in the management of melanoma, NSCLC, and other malignancies. The workshop will address the mechanism of action and uses of immune anti-CTLA4 and anti-PD1 antibodies, as well as their associated toxicities, including skin side effects, GI toxicities, oral complications, and immune-related infections, among other adverse effects.

**End of Life: Global Challenges, Local Solutions.** Andrew Davies, MD, FRCP, Vice-Chair of the Palliative Care Study Group, will lead this workshop, in which participants will consider what makes a “good death,” as well as how to plan for and manage end-of-life symptoms. This workshop will highlight the evidence for various end-of-life interventions and strategies for providing end-of-life care in challenging situations, with a focus on Australia. David Hui, MD, Chair of the Study Group and Mellar Davis, MD, FCCP, Vice-Chair, will participate in the workshop, along with other experts from Australia, the UK, and US.

**Cancer-Related Cognitive Impairment.** Alex Chan, PharmD, Vice-Chair of the Neurological Complications Study Group, will lead this workshop co-sponsored by three Study Groups: Oral Care, Skin Toxicities, and Neutropenia, Infection, and Myelosuppression. The workshop will focus on the new class of therapeutic agents known as immune checkpoint inhibitors, which play an important role in the management of melanoma, NSCLC, and other malignancies. The workshop will address the mechanism of action and uses of immune anti-CTLA4 and anti-PD1 antibodies, as well as their associated toxicities, including skin side effects, GI toxicities, oral complications, and immune-related infections, among other adverse effects.

**Nutritional Care Throughout the Advanced Cancer Journey.** The Whole Meal Deal. This workshop will be offered jointly by two Study Groups. David Hui, MD, Chair of the Palliative Care Study Group, will lead the workshop, along with Liz Isenring, PhD, Chair of the Nutrition and Cachexia Study Group and Vice-Chair Florian Strasser, MD ABHPM. Nutritional issues, such as anorexia-cachexia, bowel obstruction, and dysphagia, are common in patients with advanced cancer and are associated with significant psychosocial distress, decreased function, compromised quality of life and poorer survival. Moreover, nutritional interventions at the end of life are highly controversial. The goals of this workshop are to review existing guidelines and basic nutritional assessments relevant to advanced cancer patients. Participants will learn about novel treatments for cachexia, as well as hydration and artificial nutrition.

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**NCCN 21st Annual Conference - Advancing the Standard of Cancer Care™**

The 21st Annual Conference of the National Comprehensive Cancer Network will take place March 31 to April 2, 2016 in Hollywood, Florida, USA. The meeting brings together oncologists, nurses, pharmacists, and other healthcare professionals involved in the care of patients with cancer. This year’s agenda includes more than 25 educational sessions featuring the latest advances in oncology care, including updates on NCCN Clinical Practice Guidelines in Oncology. The sessions will be offered in a track format. More information, including a list of agenda topics and registration information, is available online at [NCCN.org](http://NCCN.org).
Profile: The MASCC Education Study Group

The MASCC Education Study Group comprises physicians, nurses, social workers, psychologists, researchers, and others with the goal of ensuring that patient education is an integral part of all aspects of supportive cancer care. As of June, 2015, the Chair of the Study Group is Paz Fernández-Ortega, RN, MSc, PhD, who succeeds Manon Lemonde, PhD, RN. Current Vice-Chairs are Manon Lemonde and Judy Phillips, DNP, FNP-BC, AOCN.

Paz Fernández-Ortega is an Associate Professor at the University of Barcelona School of Nursing and Nursing Research Coordinator at the Catalan Institute of Oncology. Besides her nursing degree, Paz holds a PhD in Methodology Nursing Sciences, as well as degrees in the fields of clinical psychology, mental health nursing, nursing management, cancer care nursing, and qualitative research in the health sciences. She has been involved in cancer care in many different settings, including inpatient, day care, chemotherapy delivery unit, outpatient, and palliative and supportive care. She has served as a member of the Executive Board of the European Oncology Nursing Society (EONS) and of the Spanish Cancer Nursing Society. In 2014, Paz received the Lifetime Achievement Award of the EONS. The award honors individuals who, during their working lifetime, have served an as inspirational leader and whose achievements have contributed to oncology nursing and to the EONS.

Manon Lemonde is an Associate Professor, Faculty of Health Sciences, at the University of Ontario (Canada) Institute of Technology and is also an Instructor at Laurentian University in Sudbury, Ontario. Besides her nursing degrees (BScN, MScN), Manon holds a PhD in Biomedical Sciences and conducted graduate research on quality of life in patients with advanced lung cancer. Her research interests include breast cancer, symptoms management, end-of-life issues, social support, and health human resources. She is also active in community work on health promotion and prevention programs for minority groups.

Judy Phillips is an Assistant Professor of Nursing at Lenoir-Rhyne University in Hickory, North Carolina (US), and is a Family Nurse Practitioner at Cancer Care of Western North Carolina in Asheville, where she specializes in hematology and oncology. Among several degrees, Judy holds a Doctorate in Nursing Practice and Certificates in Global Health and Nursing Education from Johns Hopkins University. She is currently the Lymphedema Management SIG Coordinator and an Editor for the Oncology Nursing Society.

Members of the Education Study Group have been involved in the development of the MASCC Oral Agent Teaching Tool© (MOATT). The MOATT was designed to help healthcare providers educate cancer patients who are receiving oral therapy. The standardized tool addresses all key aspects of patient assessments and teaching and can be modified to meet individual needs. The MOATT is now being used and evaluated by other researchers. Recently, Jean Boucher and colleagues published the results of a study designed to evaluate a nurse-led intervention at the Dana-Farber Cancer Institute in Boston, Massachusetts (Oncol Nurs Forum 2015 Jul 1;42(4):383-9). The tool, used to increase patient knowledge and adherence to therapy in a thoracic oncology setting, proved effective and feasible to integrate into daily practice. Other research with the MOATT is being conducted in Germany and Canada. More information about the MOATT and its development can be found on the MASCC website: http://www.mascc.org/MOATT.

Earlier this year, the Study Group conducted a survey of its members regarding their perspectives on underserved individuals with cancer and the challenges of caring for these individuals. Underserved patients are often those of low socioeconomic status, but patients may also be underserved because of their geographic location, age, gender, sexual orientation, disabilities, and language or cultural barriers. Financial limitations and low health literacy pose significant challenges in meeting the needs of many patients with cancer.

The Study Group has recently offered two pre-conference workshops at the MASCC/ISOO Annual Meetings. A 2013 workshop, titled “Improving Adherence in Elderly Receiving Oral Agents for Cancer Treatment,” addressed the difficulty of educating elderly cancer patients about adherence issues. It included topics of patient competence as a factor in adherence and safety, clinical challenges with respect to physiological, psychological, and cognitive factors, and the use of MASCC’s Oral Agent Teaching Tool© with the elderly. In 2015, the Study Group offered a workshop titled “Educational Challenges: Strategies to Provide Excellent Cancer Care to Underserved Populations.” This workshop included the results of the member survey on this topic as well as presentations and discussion of geographical differences in patients’ needs, emotional, psychosocial, and physical challenges, health literacy and cultural challenges, and educational interventions.
The MASCC Education Study Group (continued)

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In the past year, the Study Group has developed a research proposal regarding improvement of cancer patients’ knowledge about their oral cancer drugs and is currently seeking funding opportunities for this work. Other interests of the Study Group include patient education materials (e.g., on side effects of hormonal therapy), readability of MASCC brochures, general public education about cancer and its treatments, development of a health literacy assessment tool, assessment of patients’ information needs, and readability of informed consent documents.

Adverse Reactions to Cancer Drugs: The Importance of Patient Reports

A study published earlier this year in the Journal of Clinical Oncology demonstrates the considerable disparity between physician and patient reporting of adverse events associated with chemotherapy. MASCC members Jane Bryce and Ronald Feld from the Istituto Nazionale Tumori in Naples, Italy, and the Princess Margaret Hospital, Toronto, Ontario, Canada, were among the researchers who collaborated on the study.

Information about symptomatic toxicities of cancer therapy is often derived from the reports of clinicians, rather than those of patients, and this can result in underreporting of such symptoms. The aim of the study, led by Massimo di Maio of the Istituto Nazionale Tumori, was to compare patient and physician reports of toxicities in three randomized clinical trials, representing nearly 1100 patients, under the auspices of the National Cancer Institute of Naples. The group looked at six different toxicities: anorexia, nausea, vomiting, constipation, diarrhea, and hair loss. Toxicity rates reported by physicians were always lower than those reported by patients, with clinician underreporting ranging from 40.7% to 74.4%. Physicians underreported loss of appetite by nearly 75 percent, nausea by about 40 percent, vomiting by 47 percent, constipation by 70 percent, diarrhea by 51 percent, and hair loss by 65 percent. The study strongly supports the inclusion of patient-reported outcomes in clinical trials to improve precision in capturing symptomatic adverse events.

Another recent study, in which MASCC member Sandra Mitchell participated, has demonstrated the reliability and validity of the US National Cancer Institute’s Patient-Reported Outcomes version of a tool commonly used by clinicians to report patient adverse events: the Common Terminology Criteria for Adverse Events (CTCAE). The Patient-Reported Outcomes version (PRO-CTCAE), developed by the US National Cancer Institute under a contract with Memorial Sloan Kettering Cancer Center and Ethan Basch, includes a library of 78 symptom terms and 124 questions to solicit patients’ direct self-reports of symptomatic toxicities (e.g., nausea, fatigue, neuropathy, skin rash) of cancer treatment. The study of PRO-CTCAE’s measurement properties, recently reported in JAMA Oncology, was designed to assess the construct validity, test-retest reliability, and responsiveness of PRO-CTCAE items and involved a total of 975 cancer patients undergoing chemotherapy, radiation therapy, or both. Patient responses via the PRO-CTCAE were compared based on clinician-reported Eastern Cooperative Oncology Group Performance Status (ECOG PS) and responses to the European Organisation for Research and Treatment of Cancer Core Quality of Life Questionnaire (QLQ-C30). The results showed favorable validity, reliability, and responsiveness of PRO-CTCAE in this US patient sample. The PRO-CTCAE is being translated into multiple languages and studies are being conducted to guide its further development and inclusion in cancer trials.

It is not clear how much of the underreporting of symptomatic side effects associated with anticancer treatments is due to clinicians’ failure to question patients thoroughly versus patients’ reluctance or inability to describe their symptoms precisely. However, the underreporting of such side effects has implications for both research and practice and can skew the risk-benefit profiles of new cancer drugs. Giving patients a better way to have a voice can only improve both research knowledge and patient care.


Submit Your Abstract for MASCC/ISOO 2016!

Share your research and best practices in diverse aspects of supportive care in cancer at our 25th Anniversary Meeting in Adelaide. This is an ideal venue in which to present your latest findings to the international community. See the abstract submission information, including topics, at www.mascc.org/meeting. Benefit from the early acceptance process by submitting your abstract before 31 December, 2015. Meeting registration is also open with early-registration discounts of over $100.

Join us in celebration of our 25th Anniversary!

To register for updates on Adelaide, go to: www.mascc.org/meeting and enter your email!

New MASCC Members

MASCC welcomes the following new members who joined us in September:

Raymond Abratt, South Africa
Hannah Ainsworth, Australia
Jenny Casanova, Australia
Huilin Cheng, Hong Kong
Dandan Dong, China
Alvaro Dutra, Brazil
Akira Inoue, Japan
Catherine Nakayama, USA
Tracy Ruegg, USA
Thomas Smith, USA
Laisa Teleni, Australia
Elre Van Heerden, South Africa

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: Åge Schultz, MASCC Executive Director: aschultz@mascc.org

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