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Letter from the Editors

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Latest Fertility Preservation Textbook

Making decisions about fertility preservation after receiving a cancer diagnosis is a very difficult process for patients and their families. In this month's issue of the ISFP Newsletter, we hear about two groups who are on the "frontline" of patient care, oncology nurses and patient navigators. These dedicated individuals play a crucial role in guiding patients at a vulnerable time through the complex web of information about reproductive issues they may never have considered. Creative methods for patient education have been established, and the effectiveness of various decision-making tools for individual groups of patients (male, female, young adolescents, adults) is being investigated.

Communication among social scientists, counselors, oncologists and reproductive specialists is essential for providing the cancer patient with the necessary tools for customizing the best decision regarding fertility preservation that is unique to each patient.

*Every woman deserves
the chance.*

Please send us your suggestions for topics, submissions, alerts to newly published books or reviews, special recognition of members (awards, honors), meeting announcements and information that will be of interest to ISFP members.

We hope you enjoyed the Second World Congress on Fertility Preservation. Abstracts for the meeting are published in the Journal of Assisted Reproduction and Genetics, Volume 28, November 2011, and can be found at <http://www.springerlink.com/content/1058-0468/28/11/>.

S. Samuel Kim and Mary Zelinski

2nd World Congress Happenings

New Officers (2013-2015):

President:

Pedro Barri, Institut Universitari Dexeus, Barcelona, Spain

Vice President:

Pasquale Patrizio, Yale School of Medicine, New Haven, Connecticut, USA

Secretary:

Debra Gook, Royal Women's Hospital, Parkville, Victoria Australia

Treasurer:

Tommaso Falcone, Cleveland Clinic, Cleveland, Ohio USA



Abstract Prize Winners

Oral:

1st Prize - Yoni Cohen, titled "The Role of AKT1 in Ovarian Graft Reception" The Weizmann Institute of Science, Rehovot, Israel

2nd Prize - Serna Dovey, titled "Differential Antigen Expression Allows Removal of Malignant Cells from Therapeutic Spermatogonial Stem Cells (SSCs) via Fluorescence-activated Cell Sorting (FACS)" Magee Womens Research Institute, Pittsburgh, Pennsylvania, USA



Poster:

1st Prize - Mindy Christianson, titled "Experience of Young Breast Cancer Patients Regarding Fertility Preservation" Johns Hopkins University, Baltimore, Maryland, USA

2nd Prize - Lital Kalich-Philosoph, titled "AS101 Protective Effective Against Chemotherapy-induced Ovarian Damage: A Novel Approach For Fertility Preservation" Chaim Sheba Medical Center, Tel Hashomer, Israel



2nd Prize - Christiani Amorim, titled "Impact of Freezing and Thawing of Human Ovarian Tissue on Follicle Growth After Long-term Xenotransplantation" Université Catholique de Louvain, Brussels, Belgium



Editorial



Moffitt Cancer Center Health Outcomes and Behavior

Alison Nelson, B.S. and Nicole Hutchins, B.A., Gwendolyn Quinn, Ph.D.
and Susan Vadaparampil, Ph.D., MPH

The Role of the Oncology Nurse in Facilitating Discussions about Reproductive Health among Adolescent and Young Adult Populations

Fertility Preservation



Program

Advances in treatment, screening, and early diagnosis of pediatric cancers have turned a historically fatal diagnosis for children and adolescents into an 80% survival rateⁱ. The increase in pediatric cancer survivors over the past forty years demands a critical examination of the quality of life issues in survivorship, including fertility preservation and other reproductive health issues. It is no longer enough to have survival; quality survivorship is warranted. Healthcare professionals must initiate critical quality of life discussions with these patients and, in most cases, their families at the time of diagnosis to ensure every patient has the opportunity to consider all family building options based on the latest available technology.

Cancer treatments such as surgery, radiation, and chemotherapy may negatively affect a patient's reproductive ability, leading in many cases to infertility or sterility. Based on the increasing availability of fertility preservation optionsⁱⁱ and ethical guidelines of approaching adolescent and young adult (AYA) patients, this critical quality of life issue must be integrated into the overall AYA patient care. However, research indicates that, although fertility preservation (FP) discussions are advocated by the American Society of Clinical Oncology (2006) and the American Academy of Pediatrics (2008), many healthcare providers are not informing patients or referring them to appropriate specialistsⁱⁱⁱ. Further, survivors who were not informed about possible infertility may experience remorse and regret from this missed opportunity.

Oncology nurses are in an ideal position to discuss FP and reproductive health with patients and their families, compared to other healthcare professionals, given their multiple interactions prior to cancer treatment^{iv}. Yet Vadaparampil et al. found 73% of oncology nurses surveyed reported discussing FP options less than 10% of the time^v. This lack of communication about FP may be due to a lack of institutional guidelines, educational materials and resources^{vi}, the absence of oncology nurse training on the topics of FP and reproductive health, and patient-related barriers including time constraints, comfort level, financial considerations, patient characteristics, and priority of discussions^{vii}.

Editorial (continued)

It is evident that further research is needed to develop evidence-based clinical guidelines for these FP interventions^{viii}. Discussions should be appropriate for the patient's developmental stage, sensitive to the patient's emotional state, and, if age appropriate, must consider the patient's desire to include family members. AYA patients and their families find open FP discussions positive and beneficial, especially as this topic emphasizes a future beyond cancer and provides reassurance to the patient and their family that the aim of treatment is cure^{ix}.

With the development of the first oncology nurse fertility preservation training program, through a National Institute of Health R25 Training Grant led by Drs. Gwendolyn Quinn and Susan Vadaparampil of the Moffitt Cancer Center, availability of dissemination and communication strategies to improve this quality of life issue for the AYA cancer survivor will increase. As cohorts of oncology nurses are trained to communicate reproductive health information and assist patients and families with decision making, it is hoped that in the future cancer survivors, who have not completed their family building will have made an active choice, as opposed to having missed an opportunity.

ⁱ Dolin et al. (2009). Medical hope, legal pitfalls: Potential legal issues in the emerging field of oncofertility. *Santa Clara L. Rev*, 49, 673-716.

ⁱⁱ Vadaparampil, S. T. et al. (2007). Institutional availability of fertility preservation. *CLIN PEDIATR*, 47, 302-305.

ⁱⁱⁱ Clayton et al. (2008). Trends in clinical practice and nurses' attitudes about fertility preservation for pediatric patients with cancer. *Oncol Nurs Forum*, 35, 249-255. See Vadaparampil, *supra* note 2

^{iv} See Clayton, *supra* note 3; King et al. (2008). Oncology nurses' perceptions of barriers to discussion of fertility preservation with patients with cancer. *Clin J Oncol Nurs*, 12, 467-476.;

^v Vadaparampil et al. (2007). Pediatric Oncology nurses' attitudes related to discussing fertility preservation with pediatric cancer patients and their families. *J Pediatr Oncol Nurs*, 24, 255-263.

^{vi} See Clayton, *supra* note 3

^{vii} See King, *supra* note 4

^{viii} See Clayton, *supra* note 3; Zakak, N. (2009). Fertility issues of childhood cancer survivors: The role of the pediatric nurse practitioner in fertility preservation. *J Pediatr Oncol Nurs*, 26, 48-59



First iPhone App on Fertility Preservation for Cancer Patients

Cancer treatment can destroy a patient's fertility, but not all health care providers are familiar with the risks and options to preserve it. Now there's an app for that.

A new iPhone app, called iSaveFertility, will give physicians, a quick reference guide for preserving the fertility of children, women and men diagnosed with cancer. The free app also contains patient fact sheets and allows providers to email these sheets to patients, in English or Spanish, at the click of a button. The app was created by the Oncofertility Consortium, a national group of scientists, researchers, and physicians dedicated to saving the fertility of cancer patients through research and education.

The Oncofertility Consortium created the app and a complementary website, SaveMyFertility.org, to help newly diagnosed patients and their physicians have a discussion about their fertility and make informed decisions about fertility preservation. Future work on the project will expand the app to additional types of handheld devices, such as the Blackberry and Android.

For print versions of physician pocket guides or to hear about the app's launch on new handheld devices, contact ktimmerman@northwestern.edu. The project was developed in partnership with the Oncofertility Consortium and The Endocrine Society. It was funded by educational grants from EMD Serono and Merck, Inc.

On the Front Lines of Fertility Preservation

Kate Waimey Timmerman, Ph.D., Program Director, Oncofertility Consortium---

Cancer and its treatment often impair the future fertility of young cancer patients. Since the 1970s, simultaneous advances in cancer treatment and reproductive technologies have paved the way for increased cancer survivorship and successful treatment of infertility (1). Treatments for other conditions, such as rheumatologic, neurologic, and hematologic diseases may also cause fertility loss (2). To maximize the numbers of young survivors who can fully recognize their reproductive potential, significant hurdles—in the education, navigation, and support of patients and providers—must be overcome. With that in mind, the Fertility Preservation Patient Navigator position was established in conjunction with the Oncofertility Consortium in 2007 (3). This new position allowed a single person to shepherd patients between their disease specialist, such as an oncologist, and reproductive treatment team.

The Fertility Preservation Patient Navigator, Kristin Smith, is pivotal to providing streamlined care to young patients looking to preserve fertility. She provides triage services and comprehensive counseling for newly diagnosed cancer patients, both in person and for patients across the country through the FERTLINE national hotline [866-708-FERT (3378)]. This critical position addresses each patient's fertility needs within the context of their individually tailored cancer management strategy, taking into consideration the priorities of both the patient and the disease specialist. The navigator provides highly personalized support services by helping young cancer patients and their families move through the sometimes challenging intersection of cancer therapy and fertility preservation treatments.

In addition to discussing options with patients, a Fertility Preservation Patient Navigator helps them navigate the complex details of fertility preservation. Depending on a patient, Smith may discuss a variety of financial, legal, ethical, or religious issues, often based on the scholarship of researchers within the Oncofertility Consortium and around the world.

She works with patients and insurance companies to have fertility preservation procedures covered by health care plans (4), and with financial programs, such as Sharing Hope, to get discounts for fertility preservation drugs, and negotiates discounts from individual fertility providers for patients (5, 6). She also works with patients as they make legal decisions about stored tissue, gametes, or embryos (7). Furthermore, Smith discusses consent issues for minors and the integration of fertility preservation with religious traditions in her work.

As a unique leader in the fertility preservation field, Kristin Smith also disseminates best practices to clinical specialists as they increase patient oncofertility care. She communicates patient educational tools, resources for providers, and her experiences leading a quarterly Oncofertility Forum for local providers to discuss recent fertility preservation cases. For more information on setting up and improving fertility preservation services, contact oncofertility@northwestern.edu.

References

1. American Cancer Society. Cancer Facts and Figures, 2006. Atlanta: American Cancer Society; 2006 Contract No.: Document Number].
2. Hirshfeld-Cytron J, Gracia C, Woodruff TK. Nonmalignant Diseases and Treatments Associated with Primary Ovarian Failure: An Expanded Role for Fertility Preservation. *J Womens Health (Larchmt)*. 2011.
3. Oncofertility Consortium (www.oncofertility.northwestern.edu).
4. Campo-Engelstein L. For the sake of consistency and fairness: why insurance companies should cover fertility preservation treatment for iatrogenic infertility. *Cancer Treat Res*. 2010;156:381-8. PMID: 3086472.
5. Sharing Hope (www.fertilehope.org).
6. Fertile Action (www.fertileaction.org).
7. Dolin G, Roberts DE, Rodriguez LM, Woodruff TK. Medical hope, legal pitfalls: potential legal issues in the emerging field of oncofertility. *Cancer Treat Res*. 2010;156:111-34. PMID: 2949971.



Newsletter Submissions

By Mary Zelinski

Instructions for submissions

Deadline for Submissions : The 1st of the month prior to the next issue: (December 1, March 1, June 1 and September 1).

Submissions: ≤ 6 pages, double-spaced; consist of a concise summary of new findings and future directions; avoid extensive review of past literature; include relevant peer-reviewed references. Submissions will be reviewed by the President of the ISFP and the Editor for content and accuracy.

Editorials: ≤ 2 pages, double-spaced; clear statement of position and sources to support this position; employ insight, diplomacy and respect; inflammatory statements will not be allowed.

Send to: Mary Zelinski at zelinski@ohsu.edu

Oncofertility YouTube Channel Launched

The Oncofertility YouTube Channel is dedicated to the distribution of video material that aids patients, providers, researchers and the public with information about fertility preservation for young cancer patients. Please take advantage of these materials in the discussions you have with advocacy groups, patients and family members as well as interested students, fellows and fellow faculty members.

Oncofertility YouTube

Channel: <http://www.youtube.com/user/oncofertility>

Of Special Note: Patients, Clinicians and Researchers talk about

Oncofertility <http://www.youtube.com/user/oncofertility#p/u/5/fnC-C-XeBxM>

New Book on Fertility Preservation



Fertility Preservation

Emerging Technologies and Clinical Applications

Seli, Emre; Agarwal, Ashok (Eds.)

2012, 2012, XVII, 407 p. 59 illus., 44 in color.

Springer, New York

Hardcover, ISBN 978-1-4419-1782-9

A growing majority of women in the western hemisphere have been delaying initiation of childbearing to later in life. Consequently, more women in their late 30s to early 40s are attempting to get pregnant for the first time than ever before. Since the incidence of most cancers increases with age, delayed childbearing results in more female cancer survivors interested in fertility preservation.

In this book, the editors provide strategies for fertility preservation in women and men who require gonadotoxic treatment. In addition, epidemiologic, ethical, medico-legal, psychologic, and social aspects of fertility preservation are discussed. Using a format that combines concise scientific background with practical methodological information and easy-to-grasp algorithms, the chapters all conform to a uniform structure, including a brief abstract, keyword glossary, step by step protocol of laboratory procedures, key issues in commentary and a list of references. The result is a unique, practical reference guide for reproductive endocrinologists, urologists, embryologists, reproductive scientists, and oncologists.

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