The Alliance for Fertility Preservation

BY AMANDA PATTON

Launched in late 2011, the Alliance for Fertility Preservation is a coalition of experts in reproductive endocrinology, urology, and oncology. Building on the American Society of Clinical Oncology (ASCO) 2006 fertility guidelines, the Alliance aims to educate and empower patients with cancer to make the best decisions about fertility preservation prior to treatment or about infertility management after treatment with a goal of promoting dialogue between patients and clinicians to help optimize both expectations and care.

The Alliance is co-chaired by John Mulhall, MD, director of the Male Sexual and Reproductive Medicine Program at Memorial Sloan-Kettering Cancer Center; Zev Rosenwaks, MD, director and physician-in-chief, of the Ronald O. Perelman and Claudia Cohen Center for Reproductive Medicine at Weill Cornell Medical College and New York Presbyterian Hospital; and Glenn Schattman, MD, of Weill Cornell Medical College, and is supported by Ferring Pharmaceuticals, Inc. *Oncology Issues* spoke with Dr. Mulhall and Dr. Rosenwaks about the newly formed Alliance for Fertility Preservation.

OI. ***What was the impetus behind the formation of the Alliance for Fertility Preservation?***

DR. MULHALL. Despite the fact the ASCO guidelines suggest that patients have discussions about fertility preservation prior to treatment, indications are that a minority of clinicians are adhering to these guidelines. The Alliance for Fertility Preservation will focus on developing a rational, comprehensive clinical care pathway for patients, to increase patient awareness, and to encourage clinicians to have a dialogue with patients.

The primary impetus behind the formation of the Alliance is to increase awareness in terms of developing educational materials to empower patients to advocate for themselves. Unfortunately, what happens in some circumstances is that physicians are making the decision for the patient. The best decisions are made when patients are in complete receipt of information. For example, a patient 25 years of age with a poor prognosis, we [physicians] may think we will just skip the fertility discussion, when in fact for that patient that fertility discussion may be hugely important. It may be the means by which they can hold on to hope going through their cancer care. What we are really trying to do is put the patients in control of their own destiny.

Although the Alliance is in the "embryonic stages" of development, future goals may include the development of a website and toolkits for clinicians.

OI. ***What's the take-home message for community cancer centers?***

DR. MULHALL. If you look at the literature, 50 percent of patients who go through cancer therapy want to have or increase the size of their family. If you look at the patients who don't have children already going into cancer therapy, 75 percent of them want to have a family or extend their family. So there is a definite need to discuss these issues with patients. There are strategies in place for helping the man and the woman with cancer—before therapy—realize their fertility potential.

So number one, there is a need. Number two, there are specialists who can help. We are very interested going forward in engaging with physicians in figuring out what it is they need.

OI. ***What are the current barriers to better patient access to information on fertility preservation?***

DR. MULHALL. The number one barrier would be time in practice. This is a complicated discussion. Rather than saying, "I don't have time to do this," maybe physicians should say, "This is not my area of expertise, Mr. or Miss Jones, and by the way, we have this physician locally and this is his or her area. We'd like you to see them to have this discussion. We don't have a lot of time to do that. You might have 48 hours. But we have a relationship with Dr. X, and he or she is going to squeeze you in to have this discussion."

OI. ***Is this need becoming more critical given the increased numbers of cancer survivors coupled with advances in the fertility field?***

DR. MULHALL. The need is becoming more critical among adolescent and young adult cancer survivors. They are not in the pediatric group where there's a lot of focus on survivorship, and they are not in the adult group. They are in the middle. They tend to have reduced access to care and less insurance. So there is a large number of adolescent and young adult patients who have testis cancer or lymphoma or leukemia, who are candidates for this discussion.

The second barrier besides time is a discomfort level. For example, we did a needs assessment at Memorial Sloan-Kettering where we surveyed cancer clinicians and asked, "Do you think this [fertility preservation] is important?" The overwhelming majority said it's hugely important. But when we asked them who would they like to give this discussion, the overwhelming majority said, "Someone else." Because they don't know what the options are—it's just a different discussion.

[The goal is that] the patient is making a rational decision based on receiving comprehensive information. I think that if you look at the bigger picture of survivorship, we're not just here to cure cancer; we're here to cure the effects of the diagnosis and the treatment of cancer. That's really the survivorship credo. Talk to the patients about options and let them make the best decision for themselves.

OI. ***Dr. Rosenwaks, what do you see as the Alliance's primary mission?***

DR. ROSENWAKS. I believe that the Alliance's most important mission is to educate oncologists and patients about the available fertility options for both males and females who face the challenges of cancer therapy. While these issues are quite familiar to reproductive endocrinologists and reproductive urologists, and in spite of the fact that these issues have been discussed and presented at ASCO and other organizations, many couples do not get this information from their oncologists.

Although most oncologists are familiar with the general field of fertility preservation, also called oncofertility, the information they have may not be as comprehensive as it needs to be. Because the Alliance is made up of a broad group of experts involved in oncology and oncofertility, namely reproductive endocrinologists, reproductive urologists, oncologists, psychologists, and patient advocates, it can develop a program that will be coordinated and useful for all the parties involved. We have an opportunity to develop educational tools that will be helpful to the oncologists, their patients, the oncology programs, and the nursing and support staff, as well as reproductive specialists.

The Alliance is being created to promote collaboration between the professional groups involved in cancer therapy and the reproductive specialists who will take care of the fertility consequences of cancer therapy. It will promote a multidisciplinary approach to fertility preservation by educating reproductive endocrinologists and oncologists about available, contemporary fertility preservation options.

OI. ***How might the Alliance for Fertility Preservation benefit community-based cancer care programs?***

DR. ROSENWAKS. We hopefully will provide these centers with up-to-date, contemporary, cutting-edge information regarding the impact of various cancer treatments on fertility and, more importantly, the options available for both male and female patients who are facing cancer treatment—whether it's radiation or chemotherapy.

An example of how I envision it working is the following. Clinical oncologists and researchers will share information on the available protocols that are more protective (fertility sparing) in terms of loss of fertility and loss of germ cells, both in the male and female. As this group will include all the parties involved, oncologists, reproductive endocrinologists, reproductive urologists, radiotherapists, patient advocates, and psychologists, it will provide [community cancer] centers with a comprehensive overview and contemporary approaches to fertility preservation. We will make all the information in this critical area of oncofertility available to community cancer centers so that they can provide their patients with appropriate treatment options. OI

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