Report from the Sixth International Symposium on Hereditary Breast and Ovarian Cancer

Living with BRCA

REPORT FROM THE LAY DAY CONFERENCE

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SUMMARY: Conference for gene mutation carriers

The Hereditary Breast and Ovarian Cancer (HBOC) Lay Day conference provides an unparalleled experience for people living with or affected by HBOC. It is entirely dedicated to gene mutation carriers, at-risk individuals and their families. It brings together the latest in medical and scientific advances in a layperson format. The conference itself runs in parallel to the scientific meeting on international HBOC that has continually attracted the top experts in the field.

GENETICS AND COUNSELLING

The day began with an introductory session on the basic principles of the genetics of breast and ovarian cancer and some of the more recent gene discoveries related to HBOC. Laura Palma, Genetic Counsellor at the McGill University Health Centre, provided a “Genetics 101” review and reminded the audience what a “typical” HBOC family looks like, who should see a genetic counsellor, where this visit can take place, and what generally occurs during a counselling session. This was followed by a presentation by Jeff Weitzel, Geneticist-Oncologist at the City of Hope National Medical Center in Duarte, California, who introduced the notion of small-nucleotide polymorphism (SNP) profiling for carriers as way to modify risk, the use of hormone replacement therapy (HRT) after oophorectomy, and recent advances in targeted treatment for carriers, notably poly(ADP-ribose) polymerase (PARP) inhibitors. The session concluded with
an insightful review of the present status of ovarian cancer screening and prevention given by Dr. Susie Lau, Gynecologist-Oncologist at the Jewish General Hospital and McGill University Health Centre. Dr. Lau clearly outlined degrees of prevention, how they relate specifically to ovarian cancer and implications for mutation carriers. She emphasized that early detection for ovarian cancer is not currently achievable and that even early diagnosis of high-grade serous ovarian cancer does not appear to impact on survival.

At the end of this first session many questions were asked of the panel and were reflective of the types of questions heard in clinical practice. They centred on the use of short-term HRT after prophylactic bilateral salpingo-oophorectomy (BSO), the use of oral contraceptives to reduce ovarian cancer risk, timing of prophylactic BSO, and whether the uterus should be removed along with the ovaries and fallopian tubes.

SURGERY ILLUSTRATED

The second session heard from surgeons who perform mastectomy and reconstruction for both affected and unaffected mutation carriers. Considering that at least one-third of carriers ultimately undergo risk-reduction surgery, and many are faced with making this challenging decision, this session was particularly pertinent. The talks were complemented with photos of various mastectomy and reconstruction options and outcomes. A balanced overview of potential outcomes was provided, as well as an emphasis on the variables affecting outcomes of surgery with reconstruction, such as breast anatomy, past radiation therapy, and the use of autologous versus prosthetic implants. The session helped distinguish between surgery for those affected by breast cancer and those undergoing a prophylactic procedure.

The audience posed insightful questions relevant to both those who had already undergone mastectomy and reconstruction, and those considering the procedure. The attendees were interested in knowing about the timing of surgery and about secondary “touch-up” surgeries and implant exchanges. In order to complete the information provided during this session, it was suggested that physical samples of both saline and textured silicone implants be provided for the attendees to view and feel.

PSYCHOSOCIAL IMPACT

The final session was dedicated to some of the psychosocial considerations for mutation carriers. Dr. Sharon Bober from the Dana-Farber Cancer Institute in Boston has expertise in sexuality and the sexual health of female mutation carriers, a topic seldom discussed in detail during clinical encounters. Dr. Bober emphasized that sexual health directly impacts quality of life, and reviewed considerations for BRCA carriers that can directly impact sexual health and intimacy, such as premature menopause after BSO and the loss of ones natural breasts and other symbols of femininity. Dr. Bober outlined how there are 3 core areas to consider when trying to understand and improve sexual health: the mind, the body and the social. Dr. Bober discussed ways to help improve upon each of these areas, with the ultimate goal of maintaining sexuality and intimacy after major risk-reducing surgeries to organs connected to sexual function.

Psychologist Dr. Karen Hurley from Memorial Sloan-Kettering Cancer Center in New York City spoke about the impact of family planning and early menopause for young carriers undergoing prophylactic BSO. The many different emotions and feelings of young women were illustrated with examples from Dr. Hurley’s research and practice. She described how patients are forced to think of their bodies as parts and not a whole, how their “biological clock is ticking,” and how young women feel like they are a “hard sell” when it comes to dating and relationships. Ultimately, Dr. Hurley reminded the group that prophylactic BSO at a young age challenges life goals, and she helped to normalize the feelings and emotions that come with this experience.

The last presentation of the day was devoted to a patient testimonial by a mother and daughter who described how a gene mutation can impact family members differently and at the same time bring them together. This personal account brought depth, context and meaning to the information provided throughout the day by experts. The speakers brought the audience through their journey from breast cancer diagnosis and treatment, to genetic testing and gene mutation identification, to the discussion with children and predictive genetic testing for a young woman, and finally to prophylactic bilateral mastectomy. The talk showed why so many experts from many different fields come together to support families affected by HBOC.

As a final activity, participants had an opportunity to participate in a “Show and Tell.” This initiative grew out of an impromptu gathering in the women’s washroom at one of the first conferences. The “Show and Tell” is now an official part of the Lay Day conference program and gives women the opportunity to reveal their mastectomy scars and outcomes of reconstruction. The women are given a private space, and many participated. This has proven an invaluable experience to those contemplating the procedure.

The Lay Day HBOC conference is an information-rich meeting covering a broad range of topics that brings together patients, their families, doctors, researchers, genetic counsellors and other healthcare professionals. It provides up-to-date information and addresses the questions and concerns of the attendees. It is a unique opportunity for the public to interact with experts and fellow carriers in a way that enriches the experience of carriers, as well as clinical practice and research related to HBOC.