

Denise Flett Report: EONS Research Travel Grant 2015
Report on visit from 12th October 2015
To Susan F. Smith Centre for Women's Cancers, the Dana Faber Cancer Institute
(DFCI) in Boston, USA

Approximately 12% of newly diagnosed breast cancer cases occur in women under the age of 45 (1). This population group face many unique challenges as they undergo multimodality treatments that should be addressed with integration of multidisciplinary care (2). Many consequences of treatment will impact negatively on quality of life for this patient group including chemotherapy induced menopause, infertility, diminished body image and reduced sexual functioning, in addition to other complex concerns (1).

In response to this growing body of evidence and patient feedback, the Royal Marsden Foundation NHS Trust have sought to initiate a new service in 2015 specifically aimed at Young Women with Breast cancer. Programme goals being the creation of a holistic patient focused service to meet the often complex and emotionally challenging needs of this patient group. My role within this programme as Advanced Nurse Practitioner for Younger Women with Breast Cancer is to augment and lead coordination and development of a service specific to these patients and also to complete a research project within the remit of younger women's support needs during and following breast cancer treatment.

A successfully established model of Support Programme for Younger Women with Breast Cancer is the 'Young And Strong Programme for Young Women with Breast Cancer' from the Susan F. Smith Centre for Women's Cancers, the Dana Faber Cancer Institute (DFCI) in Boston, USA.

This programme was established in 2005 and provides comprehensive care and support to young women confronted with the challenges of living with and beyond breast cancer. Its mission is to enhance care and education for patients and their families, as well as to advance the understanding of the biology of breast cancer and the experiences of the disease through ongoing research. At the time of my application for the EONS travel grant to visit the DFCI more than 2,600 young women had been enrolled into the 'Young and Strong' programme.

The purpose of the EONS Research Travel Grant:

My purpose was to visit the DFCI in Boston and meet with the various key 'Young and Strong' programme team members including the Director of the Programme Medical Oncologist Dr Ann Partridge, the Programme coordinator, programme researchers and other specialists involved with the various programme resources. Additional to this was to attend the annual Breast Cancer in Young Women: A Forum for Patients and Survivors event.

Objectives for the visit were to:

- Observe and learn more about the support resources included within the Young and Strong Programme and the tools enabling these.
- Establish a network with experienced researchers and clinicians and to learn about, examine and discuss approaches to develop, implement and evaluate new models of care in the breast cancer care setting.
- Establish an international network with experienced researchers to examine and develop collaborative research opportunities
- Attend the annual forum for breast cancer patients and survivors 'Breast Cancer in Younger Women Forum'

'Young and Strong' Programme Research:

Research projects associated with DFCI Young and Strong Women's Programme.

Meeting with Kim Sprunck-Harrild Programme Manager, Taylor Wesley Young Women's Programme Coordinator, Shoshana Rosenberg Research Fellow.

The programme's main research piece is the **Young Women's Breast Cancer Study** also known as **Helping Ourselves Helping Others**.

Modeled on the Nurse study, this longitudinal study of young women, aged 40 and younger, with newly diagnosed breast cancer has two endpoints measures. The primary endpoint measure being the characterization of this population in relation to disease and psychosocial concerns at diagnosis and throughout follow up; including presentation and disease biology, genetic testing, treatment pattern, quality of care, early and long term side effects and psychosocial impacts such as fertility, sexual functioning and menopausal effects.

The Secondary outcome measure is the investigation of predictors of outcome for this patient population and concordantly acceptable interventions for young women with breast cancer.

Patients are followed up for a total of 10 years after diagnosis. Evaluations include surveys every 6 months for the first three years followed by annual surveys for a subsequent 7 years. Tumour biology investigations including molecular evaluations of disease characterisation, genetic variability and hormonal levels in blood involve the collection of tumor and blood specimens.

Commencing in 2006, it is anticipated that over 1,600 women aged 40 and younger with newly diagnosed breast cancer from academic and community health care institutions will be eligible for this observational study and that 1,300 of these women will consent for inclusion. The primary completion date is estimated to be in November 2025 .

The POSITIVE Trial: Pregnancy Outcome and Safety of Interrupting Therapy for women with endocrine Responsive breast cancer.

The DFCI has recently commenced recruitment for this study that aims to investigate if temporary interruption of endocrine therapy to achieve pregnancy is associated with a higher risk of breast cancer recurrence. Additional study objectives and endpoints include: specific indicators related to fertility, pregnancy and the biology of breast cancer in young women. Interested Centres can also participate in a companion study on fertility concerns, decisional conflicts and psychological well-being for this patient cohort.

Sponsored by the International Breast Cancer Study Group (IBCSG) this multicentre study plans to recruit 500 patients over four years. The study participants will be followed for 10 years and researchers hope that safety data can be shared within 6 years.

'Young and Strong 'Programme Resources:

Family Connections- *meeting with Programme coordinator Molly Sass*

Family Connections is a Dana Faber Cancer Institute resource programme for parents with cancer and their families. Most referrals for this programme are initiated from the patient's keyworker (usually a nurse or social worker) to the Family Connections Programme Coordinator. Other notifications for this programme are found by the DFCI Website and by fliers to the wards. Programme volunteers then provide the appropriate Family Connections support pack for the parent and children.

The support packs are funded by donation and provide an age appropriate resource for children and parents. The Children's packs are age specific; ages 4-7, 7-12, and 12-16. They include an age appropriate toy, information booklet and age specific book about a parent having cancer, all contained in a blue backpack.

The Parent Pack contains a folder with information including many testimonials. There is a list of general resources, and a reading book list. There is also information regarding the national US charity 'Light One Little Candle' included in the pack <http://www.lightonelittlecandle.org/about.htm>

This charity provides free children's books to parents experiencing cancer. It enables this by providing a reading list in which a parent can choose a free book to share with their child, the objective being to help in the development of lasting memories and connections between the parent and child.

The Family Connections Programme also provides Bereavement Folders to assist with the death of a cancer patient, these are often requested by grandparents.

Parents or families requiring additional support can be referred to meet a Family Psychologist.

There is an annual Family Connections Forum for families with children aged from 6-12 years. This is a morning workshop where parents have a group meeting under the facilitation of a psychologist, whilst their children engage in a group artwork project and is followed by a shared lunch.

Soul Mates Programme – *meeting with Programme Manager and Social Worker Nancy Poorvu*

Soul Mates is a peer mentor support programme that pairs breast cancer patients with women who have been through a similar breast cancer experience. This face-to-face programme has been developed over the last year and is primarily funded by a beneficiary. The first part of the programme development was to set up Board of Trustees. This group of expert advisers includes, a Surgeon, Nurse, Patient Resource Expert, an Online Breast Programme Living Beyond Breast Cancer member, and a lymphoedema therapist.

Volunteer mentors are all at least 1 year post-diagnosis. The training for mentors includes a full day Group Work (for a group of less than 10 participants) covering 6 key modules. Topics covered include; How to deal with difficult feelings, Finding time to call; completing the programme's documentation forms and weekly reports.

All Peer Mentors are vetted. Application includes completion of the application form and an interview if successful. All Peer Mentors must complete the Dana Faber Occupational Health requirements and the 2hour mandatory Volunteer training as well as the 1 day Mentoring training. .

Peer Mentors are required to complete weekly reports and online surveys. They meet regularly for Peer Supervision as a group under the leadership of the Group Manager. Peers meet face- to -face monthly for a dinner meeting helping to facilitate an empowerment community. These dinner meetings also include an educational speaker.

Additional 'Young and Strong' Programme Services include:

-Young Women's Telephone Support Group:

This is for Young Women wishing to connect with others going through a similar breast cancer experience and who are within their first year from diagnosis.

-Genetic Testing and Fertility and Reproductive Services are also provided.

Breast Cancer in Younger Women: A Forum for Patients and Survivors

This is an annual full-day event that includes both a "patient and survivor" panel and an "Ask the Experts" panel including many key oncology clinicians. The afternoon holds small group session that are facilitated by breast oncology social workers.

"Ask The Experts" Panel: Jennifer Ligibel MD: Director of the Zakem Centre Karen Fasciano Psy.D – Lead the Young Adult Programme, Sharon Boder PH D- Sexual Health psychologist, Eric Zhou MD Sleep Psychologist, Moderated by Ann Partridge MD.

The 2015 Forum Topics also included in its programme;

"Healthy Living and Breast Cancer in Young Women" - Jennifer Ligibel MD

Dr Ligibel's presentation included two dietary trials; the Women's Interventional Nutritional Study (WINS) and The Women's Health Eating and Living (WHEL) study. The WINS study is one of first randomized controlled trials to demonstrate the effect of dietary intake on breast cancer recurrence. (3) The conclusion from this study supported the initial hypothesis that dietary fat reduction improves relapse-free survival in postmenopausal women with primary early-stage breast cancer receiving conventional cancer management.

The Women's Health Eating and Living (WHEL) Study, a multi-institutional randomized study investigated the influence of a low fat diet very high in vegetables, fruit, and fiber on prognosis following treatment for early breast cancer and concluded (during a 7.3 year follow up period) that adoption of the study diet intervention did not reduce additional breast cancer events or mortality (4).

DFCI is planning to commence the Breast Cancer Weight Loss Study (BWEL) Study in Spring 2016. This is a randomized Phase III trial deigned to evaluate the role of weight loss in adjuvant treatment of overweight and obese women with early breast cancer.

“What ‘s Hot in Breast Cancer Treatment “ Erica Mayer MD

Presented on New Treatments and Research Trials in Breast Cancer.

In summary...

PALOMA-1 is a randomised Phase 2 trial comparing palbociclib in combination with letrozole versus letrozole alone in the evaluation of progression free survival in post menopausal women with ER+ HER2-ve advanced breast cancer.

PALOMA -2 is a randomised multi centre double blind Phase 3 study that evaluates palbociclib in combination with letrozole versus letrozole plus placebo as a first line treatment for post-menopausal patients with ER+ HER2 -ve advanced breast cancer.

PALOMA- 3 is a randomised, multi centre, double blind Phase 3 study evaluating palbociclib in combination with fulvestrant versus fulvestrant plus placebo in ER+, HER2-ve metastatic breast cancer who's disease has progressed after prior endocrine therapy

PALLAS – Phase III Randomised Trial of Adjuvant ET +/- Palbociclib

NEOSPHERE- Randomised , Multi centre study evaluating of PERJETA – based neoadjuvant treatment in HER2+ breast cancer

EMILIA Study- Randomised study in HER2 +ve advanced breast cancer. Assigning patients previously treated with Trastuzumab and a taxane to T-DM1 or lapatinib plus capecitabine.

ATTEMPT Trial - Randomized Phase II Study of T-DM1 versus Paclitaxel in Combination With Trastuzumab for Stage I HER2-positive breast cancer

PARP Inhibitors studies; OLYMPIA, BRAVO, EMBRACE

IMMUNOTHERAPY

PROFILE: designed to obtain genomic information on all patients at DCFI for cancer related care.

Links to 2015 Young Women with Breast Cancer Forum Highlights

<http://www.dana-farber.org/Adult-Care/Treatment-and-Support/Treatment-Centers-and-Clinical-Services/Breast-Cancer-Treatment-Center/Young-Women-with-Breast-Cancer-Forum-Highlights.aspx>

Conclusion:

My experience visiting the ‘Young and Strong’ team from the Susan F. Smith Centre for Women’s Cancers, the Dana Faber Cancer Institute (DFCI) in Boston USA was enormously enriching both professionally and personally.

This opportunity enabled me to learn more about the support and information needs of Younger Women with breast cancer and to explore an evidence based programme framed to address these concerns. The programme has now been successfully operating for over 10 years and it was valuable to learn the design challenges and successes in its development as well as explore past, present and future research studies.

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