

**World Conference on Breast Cancer
Hamilton, Ontario
June 7-10, 2011**

The World Conference on Breast Cancer Foundation is dedicated to the international and multi-disciplinary global action on breast cancer. The conference is held every three years in Canada to serve individuals with breast cancer and the family, friends and community networks that support them. It is also an opportunity for women across the world to come together with people who are concerned about breast cancer to share common issues that impact survival and quality of life and to advance global action on breast cancer.

Each year more than one million women are diagnosed with breast cancer and approximately 400,000 die. (There were some sessions given on the incidence of breast cancer in men but the focus is on women.) ALAB is just a minute percentage of the 4 million living with this disease.

Approximately 400+ delegates from 38 countries attended this important conference sponsored by Scotiabank, CBCF and other organizations and individuals. This sixth WCBC was themed "Transcending the Breast Cancer Experience: A Global Partnership".

There were many highlights during this four day conference. The opening ceremonies on June 7th were followed by a parade of mainly silent women through downtown Hamilton. The Silent Walk of Hope was a very visible way of raising breast cancer awareness with banners decorating the streets and a motorcycle police escort. Each day opened with a sunrise breakfast networking opportunity followed by plenary sessions given by noted international workers in the field of breast cancer. Topics ranged from finding the causes of breast cancer to physical and emotional rehabilitation.

THE END OF BREAST CANCER; PROGRESS REPORT- Dr. Fran Visco, President of the US National Breast Cancer Coalition reported on the progress of their goal to end breast cancer by January 1, 2020. The NBCC works to influence, challenge, advocate the system for treatment for all. Statistics included showed that the highest number of women diagnosed with breast cancer is in the 55-65 age bracket. This group notes that there are now fewer deaths but the exact reasons are not known- likely a combination of factors. According to the NBCC there is no concrete evidence that BSE is successful in helping to reduce the number of deaths

by breast cancer but that it leads to more biopsies. NBCC has been advocating for affordable drugs for the last 20 years. There have been huge increases in US government funding for new treatments and clinical trials. The 2 key goals according to NBCC are: How to prevent metastatic breast cancer and to find the causes. Dr. Visco noted that in the US politics play a dominant role in the attitude toward any disease.

Out of the Shadows: Challenging Post Treatment Monsters- Linda Learn, Juravinski Cancer Program, Hamilton.

This program was created to meet the informational needs of women in post treatment for early stage breast cancer. The Out of the Shadows program offers a series of educational presentations by health care professionals on topics of interest. It is aimed at empowering participants to resume responsibility for their health. The program enrolls 750 new patients yearly. Among the 7000 patients treated per year the greatest fear is recurrence. Six sessions on nutrition, recurrence, exercise are given once a month to small groups 15-18 with a focus on wellness. The presenter also outlined the steps for setting up this program.

Is It Hot in Here or is It Just Me? Managing Hot Flashes After Breast Cancer- Margaret Forbes, Juravinski Cancer Centre

This presentation focused on managing hot flashes using non-drug and drug interventions. The presenter listed some common triggers for hot flashes and suggested tracking diet to look for which triggers affect you. Practical tips included dressing in layers, using fans, lowering room temperatures. She also mentioned paced breathing and meditation. She named several drugs which can be used to reduce hot flashes all of which have some side effects. CAM therapies include: Acupuncture with a possible 50% reduction, Hypnosis, and HRT. Oral HRT is not recommended post breast cancer.

UNDERSTANDING THE ROLE OF GENETICS - Dr. Funmi Olopade, Professor of Medicine and Human Genetics, Director of the US Cancer Risk Clinic
Dr. Olopade's research topics include identifying the source of ER Negative breast cancer. Scientists have discovered that abnormal cells in chromosomes are the cause of cancers such as leukemia CML which led to the development of the Gleevec drug caused remission of CML. There has been no big new cancer drug since herceptin which has been around for 20 years. Dr. Olopade talked about personalized medicine in the Genomic Era. Perhaps next year human genome testing may be available for as little as \$1000. This testing will look at genetic makeup versus cancer genome (cells) to personalize treatment. The human race shares 99.9% genetic chain- 0.1% makes the difference.

Metastatic Breast Cancer: Redefining Hope- Dr. Christine Brezden-Masley, Oncologist at St. Michael's Hospital, Toronto

Dr. Brezden-Masley spoke about the meaning of metastatic breast cancer, the variety of strategies for treatment, and the advances that have been made. She wrote the first paper on cancer fog since some types of chemotherapy may contribute to the loss of mental facility in formerly high functioning women. She would like breast cancer to be regarded as a chronic disease similar to diabetes to ensure regular treatment to prolong life. Metastatic breast cancer is not curable. Death may occur within 2-3 years. She advocates more biopsies for MBC since it is low risk and quick. There are many more treatments available now such as Avastin which blocks new blood vessel growth in tumors. A new drug, T-DMI (not yet available) is being studied in the Marganne study which is currently enrolling patients. She also mentioned Tamoxifen and Aromatase inhibitors and how they work but that there are also serious side effects.

PATIENT NAVIGATION: Barriers to getting diagnosis and treatment Dr. Harold Freeman, Ralph Lauren Foundation, NY.

American Cancer Society Initiative on the Poor.

Dr. Freeman presented a brief history of cancer initiatives in the US dating back to 1971 when the US National Cancer Act was signed to put more money into research. However there was no plan for delivery of service. The poor have not shared in the benefits. Dr. Freeman began the Patient Navigation Program to help the poor seek diagnosis and treatment. To do so they must overcome barriers: financial, communicative, medical and emotional. "No person should go untreated, lack timely treatment or be bankrupted. People should not die because they are poor."

Dr. Freeman outlined 6 principles of patient navigation.

1. Patient navigation is a patient-centric health care system delivery model concentrating on the timely movement of the patient through a given health care system.
2. The core function of patient navigation is the elimination of barriers to timely care
3. PN should be defined with a clear scope of practice that distinguishes the role of navigators.
4. Delivery of navigation services should be cost effective
5. The determination of who should navigate should be primarily decided by the level of skills required at a given phase of navigation
6. Large systems of navigation require coordination which is best carried out by assigning a navigation coordinator who is responsible for overseeing all phases of PN.

The first PN Program was initiated in 1990 in the Harlem Hospital Cancer Control Centre. By 2000 the Harlem Intervention improved the 5 year survival rate from 39% to 70%.

Three Major Factors to improve in the US:

1. Provincial screening
2. Establish patient navigation program
3. Increase outreach & public education

His organization continues to work toward the elimination of health care disparities

IS THIS WHAT WE REALLY WANTED? THE CONTEXTS AND CONTRADICTIONS OF PATIENT INVOLVEMENT

Presented by: Christina Sinding, McMaster University

The Canadian Breast Cancer Patient Charter encourages patients to seek the highest quality of care needed. However you need to be your own case manager. This can be difficult for many people.

Personal experiences:

Rose Kushner in 1974 stopped her surgeon from performing immediate surgery at the time of her biopsy. She needed to hear options.

In 2006 Robyn needed more information and the surgeon's expertise" medically, what is the best choice? The Medical team seemed reluctant to express an opinion because there are more choices in treatment, liability concerns.

Lisa called the doctor herself rather than passively waiting.

Fran asked the family doctor to assist her surgeon in her surgery; made her own surgery date and then made her own appointment with the oncologist.

Now patients need to keep their own copies of health records.

"Women who have abundant social and material resources are able (and encouraged) to bring these to bear on the health care system; women with fewer resources are less able to enact successful involvement."

INTERNATIONAL PANEL: GETTING TO KNOW YOU

This plenary session was most varied and interesting as professionals from different countries shared the challenges and struggles pertaining to the breast cancer journey in their countries.

I had the opportunity to speak with **Ranjit Kaur of Malaysia** after her session on Resource Appropriate Program Development. She was very interested in our crew traveling to her country to participate in the regatta. I will be in contact with her as our departure date draws closer.

Ranjit Kaur from Malaysia a 14 year survivor is the CEO of Breast Cancer Welfare Association Malaysia. She is also a Board Member of Reach to Recovery International.

Breast cancer is the most common cancer in Malaysia and the peak age is 40-49. Unfortunately diagnosis is often at the late stages 3 or 4. Malaysia is ethnically diverse with the main groups: Malay, Chinese, and Indian. Diagnosis is often late due to screening fear, expense, and access to treatments. Social stigma still exists. Psychosocial issues include ignorance, fear of isolation, denial, distress. There is no universal health care. Many women fear divorce or the addition of wives if they are diagnosed with cancer. Others fear that it is contagious or that it is fate and therefore suffer in silence. The Breast Cancer Welfare Association Malaysia slogan is Together Toward Wellness to educate women about breast cancer and to dispel the myths. This agency is promoting MURNI = pure good clean to change knowledge & attitude. MURNI relies on patronage to cover expenses for the pink truck which travels the country giving clinical examinations but not mammograms.

Shubha Maudgai, (India) Support /Navigation Program in existence for 40 years.

The Approach:

- Awareness Lectures in schools, factories
- Cancer screening
- Insurance- paid in one lifetime sum of 8000 rupees
- Patient care & family support
- Rehabilitation
- Provision of information

In Mumbai complete support has been given to 300,000 women including medical aid, transportation, blood bone marrow, playgroups for children, accommodation, prosthesis etc. Rehab centres produce products for sale to support the program. Mumbai & N. Delhi have 90,000 breast cancer diagnosis per year. Ninety five percent have no insurance. "The Colour of Zaitun" film followed the journey of cancer patient Avid. Patients in rehab centres make their own prosthesis in house as it is much cheaper.

**Omer Aftab (Pakistan) Pink Ribbon National Coordinator
Overcoming Cultural Barriers to Secure Social Change**

In Pakistan there is a National Breast Cancer Awareness Campaign There are very few women doctors. A tumour may be removed by the local barber. Breast Cancer is a taboo topic. The government is against women discussing cancer. Mr. Aftab notes that awareness is good but not if there is no access to treatment which is very expensive. The Federal

Ministry of Women is developing. Ironically there is a strategic alliance with 14 Pakistani Atomic Energy Commission Cancer Hospitals. The PR is trying to reach mothers through their daughters attending college.

Linda Burhansstipanov, (USA) Cherokee Nation of Oklahoma

There are 550 registered tribes. Native Patient Navigators are addressing barriers to getting care. Patients and families are involved. Fourteen are paid staff. Less than half of those diagnosed are alive after 5 years. Linda related three women's stories showing how difficult it is to get proper treatment. Barriers include the great expense: \$35,000 for stage 2 and \$80,000 for stage 3. Also the lack of understanding and late diagnosis contributes to the mortality rate.

NURSE NAVIGATORS: RAISING THE BAR IN CANCER DELIVERY: PERSPECTIVES FROM THE US & CANADA- Alison Pedersen (Canada) University of Manitoba, Tina Evans (US), Lisa Tugnette (Canada) Young survivor

Ms Pedersen noted that the whole notion of Patient Navigation is rooted in Dr. Fitch and his Supportive Care: whole body whole journey 1994.

Patient navigation training requires 2 month in Alberta. Nurse Navigation in the US is a three day session at the Freeman Institute. Training is to facilitate timely access to appropriate care and resources by individuals who know cancer. Patient Navigators are now on Vancouver Island and in Manitoba as well.

Tina Evans (US) Maryland: American Perspective

Ms Evans is an oncology nurse navigator of 9 years. She is involved in setting up a program at a community hospital.

Lisa Tugnette: Reflections of a Woman.

This session was very emotional as Lisa at 36 was diagnosed on the same day as her mother (63) was diagnosed by the same doctor with her third time. Lisa's grandmother and aunt had bilateral surgery for breast cancer. Lisa credits two nurse navigators with steering both her mother and herself through the shared journey. The Navigators arranged appointments and accompanied them as well as providing information and arranging surgeries with the same doctor in the same hospital and recovery room. Lisa is the author of Reflections of a Woman and had copies available at the session. In this same session we watched a video on Virtual Care. VC allows collaboration in real time, sharing x rays etc. anywhere, any time: "Vidyo" with any medical personnel and with patients and families. So it is a virtual meeting in rooms with cameras showing patients, families and health care workers to discuss the case by looking at test results and digital images. Dr. Barbesh just consulted with Philadelphia using a \$45

camera attached to a computer. We experienced the virtual meeting asking questions and discussing the Vidyo. It is an amazingly quick and cost effective process. Dr. Barbesh is an advocate of Virtual Care while Albert Ferrara is the manager of what is described as a secure hosted subscription site.

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CONSANGUINITY AND THE RISK OF BREAST CANCER: THE IMPORTANCE OF BREAST CANCER AWARENESS PROGRAMS.

DR. ABDULBARI BENER (QATAR)

Dr. Bener gave statistics on breast cancer rates, diagnosis and treatment for women in Qatar, a Muslim country. He noted that screening for early detection improves the success rate of treatment. Women marry early and have an average of 5 children. A high PCI allows for maids and nannies. He advocates mammograms from age 40 and teaching BSE. Dr. Bener received grants to do his study of knowledge of Breast Cancer by women of different social and educational backgrounds in Qatar. There was not as much difference as expected between average and higher educated women in attitude toward BSE and screening. Only female doctors may do it but the majority do not. Of the women surveyed: 57% do get mammograms or do BSE (68% from lack of knowledge). Other reasons include embarrassment and/or fear of finding a lump. Very detailed questions included logistics such as access to clinics and screening. Less than 25% of women perform BSE. The research was done in Health Care Centres between Dec, 2008 and April 2009. One thousand women aged 30-55 were randomly selected in these urban centres.

CANCER RELATED BRAIN FOG: ISSUES AND SOLUTIONS – HEATHER PALMER (CANADA) MAXIMUM CAPACITY

Yes it is real. How does cancer affect brain functions? Work began with seniors five years ago. A group of breast cancer survivors said that the symptoms of the elderly were similar so Dr. Palmer started to work on a program to address the brain fog. Dr. Palmer states that chemotherapy is not the only cause and that it is different from other “brain fogs”.

Dr. Palmer describes cancer-related brain fog (crbfog) symptoms:

Changes in functioning:

- Blanking out
- “forgetting” knowledge always known
- failing to connect ideas e.g. cause and effect, the bigger picture

Changes in memory:

- Reading problems such as comprehension, retention, retrieval of information

Difficulty with verbal skills e.g. incomplete emails or things that you thought you wrote in the message but did not actually write

Compromised attention and concentration- could be due to psychological issues or being distracted

Changes in executive functions (frontal lobe):

Problems with:

- expressing ideas, opinions
- mental calculations
- scheduling
- can't do multi-tasking
- sense of knowing is lost

Less coordinated motor function and altered spatial skills (misjudging space even going through a doorway).

Psychological well being is affected which in turn affects functioning.

Causes of crbfog can be numerous:

- Chemotherapy, radiation, cancer that causes the immune system to go full-time
- Cancer-related treatments such as new drugs or medicines, natural herbs
- Genetic predisposition and or other illnesses in the family
- Psychosocial disposition
- Menopause which can affect multi-tasking

Dr. Palmer has developed a program for treating the symptoms of crbfog. She notes that many of her clients were in executive positions before cancer treatments but were unable to resume these same responsibilities post treatment. Many of the strategies may be familiar to those who work in the teaching and counseling fields.

Neuroplasticity and the Brain: Key features to develop or retrieve memory:

1. whole brain activities
2. deeper encoding using external strategies such as lists, messages and internal strategies; relying on cues
3. improving strategic processing

Task Management:

STOP CLARIFY SIMPLIFY MONITOR

Present-mindedness: relax, deep breathing

What was the task?

Break it down into tiny steps.

Reduce distractions and interference.

Management of overwhelming tasks:

1. make a to do list of longstanding goals

2. pick one task
3. break it into simple steps
4. work through the steps within a reasonable time frame
5. celebrate accomplishments along the way
6. tackle the next challenge

Dr. Palmer listed ten challenges for treating crbfog:

1. acceptance of the condition
2. the need for funding for research
3. understanding the condition
4. identifying the appropriate health care professionals to treat patients
5. designing evidence-based programs to address brain fog
6. funding for these programs
7. proving that the programs work
8. equality of access
9. receiving insurance support and workplace accommodation for it
10. getting individuals to continue to use the skills learned

Her Summary:

Symptoms differ from person to person. The domains affected are memory and executive functions. These improve over time. The brain can grow, recover and develop new connections. There are currently no medications to help in this area.

The Rethink Breast Cancer Panel was very important especially for the under 50 survivors. The Rethink group addresses the needs of the younger survivors who have different issues: dating, marriage, career, health insurance, and fertility. The youngest woman on the panel of five was diagnosed at 23. ReThink Breast Cancer is centered in Toronto with branches in Calgary and Montreal. They organize high profile events to appeal to the younger survivor. There are plans to open a chapter in Vancouver.

They have an attractive website: www.rethinkbreastcancer.com

POSTER SESSIONS

There were 23 displays. Our **AIAB** poster, brochures and postcards were very popular. Susan Anthony & I spoke to many people who were interested in the fact that survivors could safely paddle dragon boats without developing lymphedema. Our website is key to spreading our message as many attendees were planning to visit it.

One of the displays by a nurse from Bairnsdale in Australia showed the team building their own boat. This nurse developed and runs an exercise program specifically to condition survivors to be able to paddle.

Other Notes:

Meeting people with common interests from around the world is exciting and inspiring. **Herb Wagner** shared his experiences with breast cancer and has a website designed to provide information and one to one support to male breast cancer patients and their families. His website is www.malebreastcancer.ca. Herb is a member of Canadians Abreast and has also paddled with a Toronto team. He wore pink everyday.

Chemo Savvy, Winnipeg had several members of their team in attendance. We shared our experiences with maintaining breast cancer teams.

Cathy (Chemo Savvy) Prusak's story is in the book "**How to Ride a Dragon**" as well as **AIAB's Brenda Tierney, Barb Mitchell(past member), and Pam Robbins (past member)**.

A young lady from Belarus, a future oncologist was inspired by her grandmother, a victim of breast cancer.

A middle-aged woman from a tiny town in Sweden had her chemotherapy treatment (for a recurrence) on Monday then arrived on Tuesday for the conference.

Break-Through Cancer Trust, Zambia had several delegates as well as support groups from the Caribbean. At the opening ceremonies a group from the Bahamas began a spontaneous sing-a-long while the sound system was being corrected.

THE EXHIBITORS

In the same large room as the poster sessions were a wide range of exhibitors including all the sponsors, therapists, companies with survivor products, an artist, and support groups. Almost all the exhibitors had items to give away: a signed copy of How to Ride a Dragon (Scotiabank) and a CD Reflections of a Woman by Lisa Tugnette.

The World Conference on Breast Cancer is an amazing event. It inspires as well as educates and is a premiere forum for networking with survivors, support groups and those involved in breast cancer research, diagnosis, treatment and rehabilitation.

Thank-you
Patricia Tanaka
President