# INTERNATIONAL BREAST CANCER PADDLERS' COMMISSION

#### VOLUME 5 ISSUE 3

NOVEMBER 2015



# Looking back while shaping the future

#### By Jane Frost

As your president it is with pride and pleasure and no small amount of emotion, I report to you on the outstanding progress made by International Breast Cancer Paddlers' Commission (IBCPC) during 2015. In this annual report I also will share exciting and challenging projects envisioned for the new year.

# Let's start with future initiatives: speaking in many languages

Inspired by Argentinian paddlers who asked for permission to translate the IBCPC newsletter into Spanish, and in keeping with our mission to be international, the Commission, with your help, is about to start making the newsletter available not only in English but also in French, Italian and Spanish. IBCPC has successfully created a multi-cultural community of people with a common experience. The time has arrived to spread our message by further uniting us in languages spoken in member countries. To do this we need your help: Can you or your teammates translate the newsletter either into French or Italian? If successful we will then expand translating to include the languages of additional member countries. Ambitious? Yes. But of such value in communicating with newly diagnosed women and men, and newly forming teams whatever language spoken. If you wish to assist in this important project contact me at president@ibcpc.com

# New foundation established by IBCPC

Thanks largely to the success of the 2014 Sarasota Festival, IBCPC is establishing a foundation which will be registered under legislation in British Columbia, Canada. It will be constituted as a non-profit organisation and be authorized to use its resources for non-charitable activities permissible for non-profit organisations. The IBCP Foundation's primary mission will be to support and encourage newly-forming teams.



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# In the past year the IBCPC accomplished the following:

- Increased IBCPC's membership to 157 teams from 14 countries. This is partly due to the enthusiasm of the twenty-six National Representatives who liaise with their member teams one-on-one; (See Impressive growth page 2)
- Selected Florence, Italy where the 2018 Participatory Festival will be hosted by the *Florence Dragon Lady Team LILT*;
- Celebrated twenty years since the founding of dragon boat paddling was established by Dr. Don McKenzie in Vancouver, B.C. Canada. Over half of the IBCPC member teams celebrated the event on June 13 with the main event held in Vancouver. (See page 3 for news about the 20 Years Abreast Celebration Momento);
- Publicized world paddling events; and
- Shared personal stories of hope and fortitude with newsletter readers.

I thank the Steering Committee Directors and the National Representatives for their commitment and continuing enjoyment in furthering the goals of the Commission, a unique organization that is changing the quality of life for people around the globe living with breast cancer. For these people, both men and women, who have suffered the trauma of the diagnosis and treatment, IBCPC is providing support, encouragement, friendship, a healthy, funfilled sport and, most importantly, hope. I have the privilege of seeing this hope almost every day. I can not imagine a greater gift to give and to receive.

To all member teams throughout the world may the New Year of 2016 bring us all love, happiness and good health.

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This gala dinner on September 8th was the XV Edition of the "Il Torrino d'oro". Every year since 2001 the association called "il Torrino di Santa Rosa" organizes this dinner in the Cestello Square in the heart of Florence along the Arno River.

On this occasion Florentine entrepreneurs and people who distinguish themselves in support of the city of Florence (for instance, social and cultural commitments) receive the TORRINO award. Founded as a neighborhood dinner of the San Frediano area, the artistic and artisan part of the city, the dinner has become a huge event with more than 2,000 people present. Every year II Torrino chooses to assign the charity lottery to one association involved in social goals. The 2015 Edition has assigned the amount of the lottery to the Florence Dragon Lady team.

Kim Bonomo, IBCPC Director, will liaise between the IBCPC Steering Committee and the Florence Festival Organising Committee responsible for the fifth IBCPC 2018 Participatory Festival. Kim was in Florence working with the Committee and was able to attend this event with the Florence team.

To:	
From:	All IBCPC Member Teams
. 1011.	The Florence Festival Organising Group (FFOG) and the International Breast Cancer Paddlers' Commission with
RE:	International Breast Cancer Paddlers' Commission (IBCPC) Attendance at Florence
Response Date:	Attendance at Florence Festival 2018
The fifth internation	

The fifth international dragon boat festival for breast cancer paddlers will take place between June and September 2018 in Florence, Italy. The FOGG and IBCPC are requesting an expression of interest from each of our member teams as to the likelihood of attending the Florence event

- Please send to <u>committee@ibcpc.com</u> the following information
  - Team name and location

Approximate number of participants: paddlers, drummers and steers Approximate number of supporters

Receiving this information will assist both the FOGG and IBCPC in the planning and organization for this exciting event. An approximate number is requested and there will be no obligation expected as a result of sending this information. I t will be used only for nlanning numbers.

Your response would be most appreciated if it could be received at the above email address by January 15, 2016. Thank you in advance for your assistance in this matter



#### Impressive worldwide growth in IBCPC membership

IBCPC Directors are greatly encouraged by the number of breast cancer dragon boat teams from all parts of the world that are joining the Commission. The following teams were recently welcomed as members: Donna Piu' Lilt Latina from Latina, Italy; Trifoglio Rosa from Mestre, Italy, Pink Amazons, Milano-Pavia, Italy and Karalis Pink Team from Cagliari, Sardinia. Ladybugs have come from Lunen, Germany and Doha

Wireless Warriors from Doha, Qatar. Hsin, Huai Dragon Boat Team hails from Tapei City, Republic of China, South Australia Dragons Abreast, Westlakes, Australia, Paddlers for Life Manchester, Manchester, United Kingdom, Wonder Women's Warriors, Crystal Beach, Canada and Team Survivor San Diego Sea Dragons have joined from San Diego California, USA.

Most exciting is the first IBCPC member team in South America which is from Buenos Aires, Argentina: Remaras Rosas La Plata. With the Remaras membership the IBCPC now has representation on six continents and the IBCPC membership numbers one hundred and fifty-seven teams.

#### Balancing health and competition vital

#### **By Dr Don McKenzie** Vancouver, Canada

There is no such thing as a 'bad day' in my world. If things get busy, complicated or uncomfortable I just take a look at a card or letter received from a paddler who explains what a treat it is to be alive and leading a full, active life after breast cancer. That puts everything into the proper perspective and the world begins to turn once again. Thank you for that!

In the first year or two, most of the correspondence was about recovering from the disease, gaining control of your life through paddling and the impact the program had on families, friends and loved ones. Many of the letters were very personal and it was a privilege to read them. Gradually the messages began to focus on the sport, the dragon boat races themselves. I learned how teams were training, how to build a dragon boat, comments on technique and how a particular crew had won a race, collected several medals or were preparing to compete in local or international regattas. The shift from health to competition had begun.

Twenty years after we started, there are still lots of places that are just beginning a program in breast cancer dragon boat paddling. Although there are countries where exercise for cancer patients is still frowned upon, many locations in Europe have discovered this paddling program and are rapidly adapting to it.

A month ago, in Rio at a test event for the 2016 Olympic Games, I met with

**Dr. Christina May Moran de Brito**, a physiatrist from Sao Paolo, Brazil. She has started a rowing program for cancer patients and is very keen on expanding to dragon boats, once they are more readily available. Christina, along with **Adriana Bartoli** from Canada are set on developing programs for women in Brazil and Argentina. Special women indeed.

With these new teams many of the same questions that were asked 20 years ago are still relevant. In each case it still appears the original focus is on recovery from the disease, avoiding lymphedema and regaining control of your life. An overriding goal is safety; exercise and cancer is still a foreign place to go, at least initially. Once confidence in the program is developed, myths dispelled and a positive outcome in terms of health and lifestyle is achieved, then the competitive spirit comes into play. This is completely understandable, a natural evolution, but serving two masters creates conflict and proper perspective is important. As your team evolves and competition may become the focus, realize that you may be creating a barrier for the new survivor who looks to you for help in getting away from the spectrum of breast cancer. There is a need to achieve a balance between health and competition. The take home messagerespect your roots and remember why you started this program in the first place.

# Dr. Don McKenzie



Dr Don McKenzie is the founding doctor of the breast cancer dragon boat movement which began in Vancouver, Canada in 1996. After the success of that first year Don continues his research on exercise and breast cancer. Today there are breast cancer dragon boat teams on 14 continents thanks to his efforts and those of many others, including the IBCPC.

Not only does Don work with breast cancer paddlers all around the world he is also a member of the Medical Committees of the International Canoe Federation and the International Olympic Committee. He has been physician to the Canadian National Canoe Team since 1981and has attended each summer Olympics since 1984.

Dr Don writes a regular column for the IBCPC Newsletter and you can submit questions to him by emailing committee@ibcpc.com



Don took the opportunity to meet with **Dr Christina May Moran de Brito**, a physiatrist from Sao Paolo, Brazil interested in a paddling program for cancer patients while he was in Rio de Janeiro for a 2016 Olympic test event.

## "Our Stories" Celebrating 20 years of breast cancer paddling



On December 1, 2015 the 20 Years Abreast Celebration Memento will be posted at www.ibcpc.com. Teams will be able to read the document on line by visiting the IBCPC website. Thank you to the almost 100 teams who submitted their stories.

# FUNDRAISING



#### Scars as artwork? One team's unique project

**By Michelle Blackburn** Dragons of Hope, Thunder Bay, Canada

Shortly after I was diagnosed with breast cancer (2010) I was told about the *Dragons* of *Hope* breast cancer survivor dragon boat team in Thunder Bay. At the age of 28 I never would have thought I would join them. In May 2011, I went to my first practice; I could never have known how much that would change my life.

The powerful sisterhood that is the *Dragons* of *Hope* taught me that there is life (and humour) in survivorship. We are fortunate to have three supporters on our team who exemplify what it means to stand by your loved ones. I got stronger just by being around them; so when I created The Butterfly Story I knew I wanted the dragons to participate.

The Butterfly Story transforms breast cancer survivors' scars and bodies into works of art that represent poignant aspects of their journey including symbols of strength, hope, and important people/places. It began with my desire to transform my scars into artwork, which lead to a desire to bring this experience to others. Our incredible creative team made up of **Chantal Ouellette** (artist), **Izabela Pioro** (photographer), and our hair stylists have volunteered their time to create unique transformations for our survivor participants. In addition to our individual participants, it was my wish to see a transformation for our dragon boat team.

The team's photo shoots were done over three sessions in order to capture everyone. Meticulous care was taken to ensure that the finished image would fully connect us. The Dragons of Hope were close before, but this experience brought it to a new level. We had our hair and make up done, and then shed our tops in order to be painted. Each of our scars tell a different story, but once the dragon was painted over top of us, the scars were no longer visible and we became one.

The finished image was revealed for the first time at The Butterfly Story gala event on September 25th in Thunder Bay. That evening also saw the reveal of the 20 individual survivors' images. Many of our team members were there with their loved ones that night. It was an inspiring and humbling evening to be a part of. To see such beauty that can exist in spite of cancer was breathtaking. We plan on continuing to bring this project to survivors, and look forward to sharing it with the world. For more information please visit our facebook page: https://www.facebook.com/ thebutterflystorythunderbay

# The varied aspects of fundraising

**Eleanor Nielsen,** Dragons Abreast, Toronto, Canada **Carol Mutton,** Survivors Abreast, Peterborough, Canada

#### **IBCPC** Directors

Since the announcement of the 2018 IBCPC Festival in Florence, Italy, there has been much excitement and discussion among

members on how to fund international travel. Policies vary between countries, and between teams within countries. A few of the approaches we have heard about are included here for your information.

Many teams fundraise or seek sponsorship within their own community. In most situations, this money goes to boats, mooring, coaches and costs related to practice and registration in festivals. Some cover the team uniform and other equipment e.g. a personal flotation device. In other words, the cost of "getting in the boat" and racing fees are covered by the team. The big variable is the individual members' travel costs. Some teams give members a portion of the costs of travel for use as the individual sees fit. Others consider travel costs, local or international to be the responsibility of the individual and still others put considerable effort into fundraising to cover travel and accommodation for all.

Those that fundraise, do so via various methods – games nights, social events, raffles, team building dragon boat outings, *continued on page 5* 

#### F U N D R A I S I N G

#### The Varied Aspects...continued from page 4

sale of jewelry or other products and countless other activities. Those that seek sponsorship have an equally wide range of sources. Some have corporate sponsors, others health organizations or small local businesses. The common factor is an appreciation of the assistance they receive and attention to keeping a positive relationship with the sponsor.

One issue that arose for teams whose policy is not to fund international travel is that it may always be the same team members who can finance their own travel that attend international events. Is it an issue that the same team members might always be left behind as they cannot afford the costs of international travel?

Further, are newer members encouraged and supported so that they can experience an IBCPC festival?

If you are interested, the following three discussion questions will be posted on the IBCPC Facebook page for you to comment on: https://facebook.com/IBCPC/timeline/

1) How has your team decided to address these issues?

2) What creative, unique, relatively simple and easy to resource fundraising ventures have worked for your team?

3) Do you have sponsors and, if so what is your relationship with them?

#### Australia's Dragons Abreast raises \$146,550

**By Angie O'Reilly** Festival Project Manager Dragons Abreast Australia

The 8th Annual Dragons *Abreast Australia* (DAA) dragon boat Festival was held on Cockle Bay, Darling Harbour in the heart of Sydney on 24th October 2015. This annual event was conceived initially as a means of bringing together the breast cancer survivor groups, which are part of DAA's nationwide family, as well as others who have shared our journey in the interest of 'spreading the awareness word'. There are now four categories in our Festival including Dragons Abreast, Hospitals, Social and Corporates.

This year saw some of our International dragon boat family joining in, with 14 members from New Zealand teams including *Simply the Breast,* Blenheim, *Abreast of Life,* Canterbury and *Wairarapa Dragon Boat Club* and one very happy **Kathy Ng** from *Dragons Abreast* Toronto, Canada. To top their weekend off their composite team, '*Dragons Abreast Team Inspiration*' (which included Australian members from *DA Canberra* and *DA Devonport*) won the DA Minor final. Rumor has it a 2016 campaign is already in the planning!

Forty teams, including twelve crews in the Dragons Abreast category (a record!) had a wonderful day with perfect weather and 100% smiles all round. Our fundraising target for registration/donations was \$150,000 and it currently stands at \$146,550.10, so close!

There were prizes for best dressed, with IBCPC member group DAM Busters Dragons Abreast Melbourne taking out first prize with their colourful Flamingo outfits. There were trophies and medals for each category as well as raffles and prizes for the best tweet and selfie being held throughout the day – never were there so many phones up in the air! The day's highlights included the Chinese Youth League Lion Dancers performing with their colourful dragons as well as the very moving Flowers on the Water<sup>™</sup> where six boats filled with breast cancer survivors rafted together, observed a minute's silence then scattered beautiful rose petals on the Harbour in memory of our 'Angel's Abreast' whilst listening to our theme song 'Remember Me'.

Dragons Abreast Australia is a national body with 35 member groups from all over the country. While there are some breast cancer survivor teams in Australia which are not part of the DAA family, the majority are and these share in the many benefits which a national organisation can provide. Foremost is a seat and vote on the National body, the Australian Dragon Boat Federation and an equal say on how this sport of ours is administered and developed.

As with any organisation the challenge is to ensure financial viability and this is where the Annual Dragons Abreast Festival comes into its own. Breast cancer survivor dragon boat festivals, with their sea of pink and air of festivity, provide a spectacle wherever they are held. Coupled with the many tourists who frequent Sydney, the Festival acts as a magnet to locals who come to support their team or to simply enjoy the atmosphere. As well as funds raised from entrance fees, merchandise sales, raffle and event support concessions, those participating are encouraged to fundraise and are awarded for doing so. Income from the Festival goes a long way to defray the costs of providing the national integrated support to our 35 member groups.



*Dragons Abreast Australia's Pittwater Pinks* are pictured here in Darling Harbour, in their home locale of Sydney, Australia where they paddled with 13 other breast cancer teams.



#### Sue Gie named South African Representative



**Sue Gie** who lives in the beautiful city of Cape Town, South Africa was diagnosed with breast cancer in 2012. She made up her mind cancer was not going to take over her life. After all, she

had a husband and three gorgeous kids to live for and she had to move on.

After enduring all the hardship associated with breast cancer diagnosis and treatment, she joined the *AmaBele Belles* dragon boat racing team, Cape Town's own breast cancer survivor team. Her greatest accomplishment was representing her country in Malaysia at the World Championships in the breast cancer survivor races in 2014. Here she was, someone who was never really sporty but fairly fit, competing like this. Her family nearly fell off their chairs with surprise, but what an added blessing it was. She had never done any international travelling.

Strange as it seems, she now can say thank you to cancer for opening up a whole new world of opportunities through the wonderful sport of dragon boating. She has met the most amazing people and has made many new connections with breast cancer paddlers, all partners in a journey of breast cancer dragon boat paddling. She can now take pride in her new role as South Africa's new National Representative for the International Breast Cancer Paddlers' Commission.



### Paddlers' exhibit displayed in Rome's hospitals



Behind this group of paddlers and medical personel is a photo exhibit of breast cancer dragon boat paddlers. The paddlers are from the team *Pagaie Rosa* - *Pink Butterfly* from Rome, Italy.

Recently their exhibit was placed in five of Rome's hospitals and the photos will remain in the hospitals for six months. The Italian Ministry of Health and the Municipality of Rome gave their official support to the breast cancer paddlers.

To quote **Mariagrazia Punza**, IBCPC Italian National Representative: "Every picture tells a story from the paddler to the breast cancer patient. During the exhibition's inauguration many doctors, nurses and patients saw our pictures and were amazed. We are very proud of the effectiveness of the exhibit in telling our story."





See page 7 Survivorship theme for UK Conference

#### Health care professionals join survivors in warm up



Sixteen teams made up of cancer survivors from Lancashire, Cumbria, Manchester, Edinburgh and Dundee as well as teams from Glaxo Smith Klein and local

health care professionals warmed up together on the lawn of the Low Wood Hotel at Lake Windermere, England.

#### IBCPC welcomes first German team

#### By Anke Appelbaum Ladybugs, Luenen, Germany



Why do we paddle a dragon boat? It's easy: we love it! But, in addition: Canadian medical studies showed that dragon boat paddling has positive effects on women suffering from breast

cancer: back muscles and shoulders are trained, which may minimize the risk of lymphoedema. And the mental benefits are obvious: breast cancer with all its treatments is a heavy burden. It definitely helps talking to other women who experienced similar situations - and survived. The well known phrase 'We're all in the same boat' has a very specific meaning for all pink paddlers in the world.

This year was really full of important steps for our team. It started with difficulties. We had to change our supporting dragon boat team. And with this, some of our members left the *Ladybugs*. It was something like a total restart. But today, looking back, we can say: we made it, *Ladybugs* are back again. With Luenen Lions, we found a great support team with excellent trainers. We successfully started looking for new members by distributing flyers to all nearby hospitals. We showed up with information during a locally organized "week against cancer". Some of us took part in training camps and we were part of the great event in Florence May, 2015. And we got the chance to join the IBCPC!

We're back again with more plans: At the moment, we're training together with a sports team, all in one boat. This is great - on the

one hand, but on the other hand, it's really hard for new members. Our dream is to have our own pink five bench boat. We're looking for sponsors and are already halfway.....

We really appreciate being part of the international pink paddlers. It underlines what the *Ladybugs* feel whenever we come together: it makes us stronger acting as a team!



The Volksbank Selm-Bork, Altlunen representative presents the Ladybugs a cheque to support their efforts to purchase a ten person dragon boat.

# Survivorship theme for UK Conference

**By Sue Cogley** *Paddlers for Life UK* Windermere, England



On a sunny weekend in September 2015, *Paddlers for Life UK* hosted a two day event: the North West Breast Cancer Survivorship Conference and the Dragon Bay Dragon Boat

Regatta. Both events were held at the Low Wood Hotel, Windermere and Sports Centre with support from the Low Wood Hotel and the Rosemere Cancer Foundation.

The Conference was attended by a diverse group of forty local and national health

care professionals and some survivors. The theme was survivorship and to quote the organisers: "The hardest time is after your cancer treatment finishes - that's when what you really face begins to sink in". They focused on two aspects : firstly, life after treatment and some of the fundamental issues for survivors – managing the side effects of treatment, returning to work and what it means to live well after cancer and secondly, the support services available their ongoing development and the fostering of partnerships between clinicians across the health care settings.

A particular focus was to show clinicians the role of exercise in providing recovery after treatment and as a preventative in recurrence for people in remission. With this in mind the goal of the regatta was to show the medical sector why breast cancer survivors are dragon boating. Paddlers for Life UK joined forces with the local radiotherapy unit at Royal Preston Hospital, treatment centre serving cancer patients in Lancashire and Cumbria, and the charity 'Rosemere'. Together they went to the different departments in the hospital and recruited teams for the regatta. In the end they had teams from pathology, oncology, occupational therapy, breast care and some general practitioners. Also participating were some local business teams.

The two days were a resounding success and next year's event will undoubtedly attract more health care professionals.

For a full account go to www.paddlersforlifeUK

### The Word is Getting Out: Thanks to You!

#### **By Sandra K. Rosenberg** MD, FABPMR, FACCWS University of Minnesota, USA

At the 2014 IBCPC Dragon Boat Festival in Sarasota, Florida, the Dragon Divas of St. Paul, Minnesota distributed guestionnaires studying breast cancer, lymphedema and quality of life (QOL). The questions looked at four domains of life including pain and functioning, mental functioning and household/mobility/life and social activities. Over 1000 guestionnaires were returned from 8 countries. The Divas are partnering with Dr. Sandra K. Rosenberg MD, FABPMR, FACCWS of the HealthEast Care System and Dr. Linda Koehler PhD, PT, CLT-LANA of the University of Minnesota. The main goal of the project was to increase medical awareness on the benefits of dragon boat racing exercise for breast cancer survivors. The initial data was accepted for presentation at the 25th World Congress of

Lymphology (WCOL) in San Francisco in September. Initial analysis looked at those reporting a diagnosis of lymphedema verses those with symptoms, but not diagnosed. QOL measures were similar between groups. Dr. Rosenberg, a physician and breast cancer dragon boat racer, presented the data on September 9th, 2015.

The present data is very preliminary. A significant amount of data still needs to be analyzed. Comparisons will be done studying racers with lymphedema and those without, compare data from different countries and investigating the different aspects of QOL within the different domains surveyed. The research team also includes Dragon Diva and student, **Jennifer Thorup**, and Dr. Koehler's physical therapy research students, **Christian Metz, Kayley Mikolajczyk, Sami Monson, Aleksi Moran**.

The group hopes to submit further results of the research for publication and presentation at future conferences. We want to thank the IBCPC for allowing us to collect this date and all survey participants. As the IBCPC has stated, "As the breast cancer dragon boat movement grows internationally, we have a unique opportunity to raise awareness about the disease and about life after breast cancer. We know a full and active life is possible. ... Together we are stronger, our voices are louder and the message is clearer."



From left to right Jen Thorup, Rebecca Rosenberg, Sandra Rosenberg M.D., Linda LKoehler. Ph. D.

## What in the World is Going On?

January 17, 2016 Christchurch, New Zealand Akarora Super 12 including the LeMans race

#### March 19, 2016

Sarasota, Florida, USA Nathan Benderson Park Revisit IBCPC 2014 Festival site & paddle with Florida breast cancer teams



March 19 & 20, 2016 Lake Hood, Ashburton, New Zealand New Zealand Dragon Boat Association National Championships

March 26 & 27, 2016 Lo Pagan Beach, San Pedro del Pinatar, Spain 4th International Festival and 2nd breast cancer event for this organization www.dragonboatpinatar.com





#### May 12, 2016 TBC by Dec 1, 2015 Florence, Italy Pink Dragon Lady event a week after Venice's Vogalonga www.florencedragonlady.it





The IBCPC invites teams to post events of interest to paddlers on the above Bulletin Board. To do so email the information to newsletter@ibcpc.com. The IBCPC takes no responsibility for events by reason of the posting. Where travel to another country is involved, teams are advised to consult their respective Government's Travel Advisory.

**PROVISO**: The information published in this newsletter is provided to us by the named authors, sources and other third parties and while we believe the information to be reliable we have not fully investigated all such information and we can not accept responsibility for the truth or accuracy of the same. Accordingly, International Breast Cancer Paddlers' Commission and those associated with the Commission and Jane Frost, IBCPC President, disclaim responsibility for the truth and accuracy of the information in this newsletter.

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IBCPC is a commission of the International Dragon Boat Federation