



The Belinda Sue Fund®

for Ovarian Cancer Awareness & Research

NEWSLETTER

Volume 2, Issue 1

May 2013

Our Second Annual Gala... What a Night!

The Belinda Sue Fund's 2nd Annual Gala was held on Friday, May 10th at The Henry in Dearborn, Michigan. And what a night it was with 220 guests in attendance! The event featured both a silent and live auction with almost \$10,000 raised in the auction items alone! In addition, we had very talented musicians from the Orchard Lake Philharmonic Society volunteer their time to play during the cocktail hour. The sounds of the string instruments were pleasing to the ear while folks milled about bidding on silent auction items and socializing with friends. The cocktail hour was followed by a delicious dinner in the ballroom.

Following dinner, the highlight of the evening was the presentation of awards and the live auction. Elise C. Kohn, MD of the National Cancer Institute received the "Making a Difference" Award for her contribution to Ovarian Cancer Research. Dr. Kohn was unable to attend the event in person, but we were fortunate to have a live Skype session with her where she gave a very informative presentation and graciously accepted the award. In addition to the award, The Belinda Sue Fund presented Dr. Kohn with a \$5,000 check to further advance her research in Ovarian Cancer. The second award presented that evening was the "Angel on Earth" Award given to co-recipients, Keli Giannini and DeAnn Sturdivant. Keli, a home health aide, and DeAnn, a registered nurse, both work for Henry Ford Hospice Macomb and cared for Bindy while she was in Hospice. Keli and DeAnn go above and beyond in their care for terminally ill patients on a daily basis and really make patients' final weeks as comfortable as possible. They were both very deserving of the award and truly are "Angels on earth!"

The evening's formal program concluded with a live auction with Tom Nantais as the "auctioneer." There were some great bidding wars on a couple of the items making the live auction a fun and exciting part of the program. Finally, guests enjoyed the remainder of the night dancing to live music from the band "Generations." Folks also had fun posing with great props in a photo booth provided by Memory Snappers. Everyone using the photo booth was able to print off filmstrips of their photos making for a great memory which they could take home.

Overall, it was a very successful night. Approximately \$25,000 was raised at the event. And to date, The Belinda Sue Fund is approaching \$200,000 in donations received! We are very appreciative of you, our supporters, who are helping to make a valuable difference in Ovarian Cancer Awareness & Research!

(To see a few photos of the event go to page 3)

Testing for BRCA 1 & BRCA 2

The actress, Angelina Jolie, made news in early May after disclosing she underwent a prophylactic double mastectomy earlier in the year following confirmation that she carries the **BR**east **C**ancer Susceptibility Gene 1 (BRCA1). Angelina's mother passed away from Ovarian Cancer at age 56. Jolie also lost her aunt (her mother's sister) to Breast Cancer over this year's Memorial Day weekend at age 61. Her aunt also carried the BRCA1 faulty gene. In an earlier issue, we featured Caroline Maykovich (daughter of Tom and Bindy Nantais) who carries the same BRCA1 genetic mutation inherited from her mother. BRCA1 and BRCA2 mutated genes significantly increase a woman's chances of acquiring Breast and Ovarian Cancers. In fact, the singer and former American Idol judge, Kara DioGuardi, tested positive for the BRCA2 faulty gene and underwent a prophylactic hysterectomy last year. She is considering a possible preventative mastectomy in the future if her doctor recommends it. Kara lost her mother to Ovarian Cancer at age 50 and her grandmother to Breast Cancer.

It is important for both women AND men who have a history of Ovarian Cancer in their families to discuss with their healthcare providers about having genetic testing for BRCA1 and BRCA2 mutations. Angelina Jolie and Kara DioGuardi along with Caroline (Bindy's own daughter) all feel that this testing has saved their lives. They are now completely informed of their risks for developing these and other cancers and are taking appropriate measures to mitigate such risks. While it is not easy hearing that one could be a carrier of the BRCA 1 or BRCA2 susceptibility gene, the alternative of not knowing could end up being tougher to deal with down the road.

INSIDE THIS ISSUE

- 1 Our 2nd Annual Gala...What a Night!**
- 1 Testing for BRCA 1 & BRCA 2**
- 2 A Young Scientist Discovers...**
- 2 A Personal Message**
- 3 In the Spotlight**
- 3 Did You Know?**
- 3 Getting Ready for Our 2nd Annual Zoo Walk!!**
- 3 Make a Donation & Save-the-Date!!**

A Young Scientist Discovers an Ovarian Cancer Early Detection Test

Jack Andraka, a young 15-year-old scientist, was awarded the Gordon E. Moore Award at the Intel Science Fair in 2012 for his work in developing a very inexpensive test that detects the increase of the protein, mesothelin, which can indicate the presence of Pancreatic, Ovarian, and Lung Cancers in their earliest stages. Andraka had an uncle die from Pancreatic Cancer and so was inspired to find a rapid, inexpensive tool to identify the disease in its early stages. The young scientist was in Biology class in his freshman year of high school when he was reading about analytical methods using carbon nanotubes while his teacher was lecturing on antibodies. Jack combined the two ideas and developed a strip test (similar to that of a diabetic test strip) which detects the levels of mesothelin, a cancer biomarker for Pancreatic, Ovarian, and Lung Cancers, in the blood. According to Andraka, it is far less expensive than the current diagnostic tests, AND only takes 5 minutes to run. Jack wrote to 200 professors at Johns Hopkins University and the National Institutes of Health with a plan and budget in order to receive laboratory help. Only one professor, Dr. Anirban Maitra (Professor of Pathology, Oncology, and Chemical & Biomolecular Engineering), at Johns Hopkins School of Medicine responded and invited Andraka to his laboratory and assisted him in developing his dipstick-type test. Andraka's study concludes that the test is more than 90% accurate in detecting the presence of mesothelin. Andraka has patented his testing method and is in talks with companies to eventually bring this test to market in the next several years.

A Personal Message

Every issue we feature a special message or personal story of someone who is affected by Ovarian Cancer either directly or indirectly. In this issue we highlight the story of Harper Botorowicz, an Ovarian Cancer Survivor.

At the age of 24, Harper had no idea what Ovarian Cancer was. At the age of 25, she was all too aware of the signs and symptoms. Harper always lived a fairly healthy lifestyle, being active in sports, dance, and clubs. She also became a vegan in elementary school and modeled in her teenage years through her 20s. She was always very aware of her body. At age 25, Harper was feeling bloated, having nausea, feeling full quickly, losing weight, and experiencing occasional dizziness/lightheadedness. She knew something was wrong. Harper went to the doctor and the first thought was to check her endometriosis (which she had inherited from her mother and grandmother). Her doctor also told her she might be pregnant, so she was tested: Negative. Harper saw a second doctor who also told her she might be pregnant. She assured him that she had already been tested, and that it would also be next to impossible because she had not been sexually active for months during this time of discomfort. Harper consulted a third doctor who went so far as to tell her that she was just suffering from "Young Mother's Syndrome" - basically it was all in her head.

It was at this point, Harper knew she needed to start doing some research. She only had a family history of endometriosis, not cancer. Harper consulted yet another doctor and asked to be given the CA 125 blood test, along with a couple other tests she had read about online. After some hesitation from the doctor, because he felt the test was unreliable due to no family history of Ovarian Cancer and being so young it seemed nearly impossible that it would be the cause of her pain and discomfort, she was finally given the test- which came back positive. Her immediate response was to leave the doctor's office. Even though it had been Harper's idea to run the test, when the results came back not in her favor, she couldn't accept them. Hearing the words, "You have Ovarian Cancer" made her feel weak, like a victim or a statistic and she is not either of those things. When Harper finally made her way back to the doctor's office, she was confused and depressed. She had no idea what was in store for her.

Harper was diagnosed with Stage 1 Ovarian Cancer and underwent surgery and treatment immediately. She was given the option of a partial hysterectomy due to her young age and only one of her ovaries infected. She opted for the

See "A Personal Message" (next column)

"A Personal Message" (con't)

partial hysterectomy. Harper went through the motions, but honestly did not deal with having cancer at the outset. She ignored it and had the surgery like it was just another endometriosis surgery. She was still in shock and disbelief. It wasn't until Harper began her four rounds of chemotherapy that everything started to settle in. The first round was not too bad. But she recalls sitting in the chair, looking around at other patients...feeling sorry for herself because most of the women around her were well into their 50s or older. Then she saw a little girl. She asked the young girl what type of cancer she had and her age....she was 8 years old and had Ovarian Cancer.

Throughout the course of Harper's treatment, she felt depressed. She felt like she had lost a part of her that made her a woman, making her feel less desirable. Then she started to deepen her yoga practice because she had heard that meditation and yoga could help. It saved Harper. She began to find the positive in something she had once found so negative. She looked around at all the people in the chemo centers, not just with Ovarian Cancer, but everyone fighting his/her own battle. It was inspiring and she realized that feeling depressed and not like a "whole woman" seemed silly. Harper knew that she was blessed with the opportunity to meet such strong, brave souls who were fighting for their lives...not just for a day, but for months and years. She also began knitting hats. Harper wanted to give back to the people around her who inspired her because of their strength and determination to beat a disease that doesn't necessarily have a cure or is an easy route to travel.

Harper is currently in remission and has a new drive and passion for life. In the past, she modeled and had been in an industry where everything is only surface/skin deep. Because of cancer, she realized she wanted to be involved in an industry that treats the whole body, mind, and soul. She not only practices yoga, but teaches it as well. She hopes one day to be able to work with the cancer community through yoga and share the light that so brightly guided her back to health. Harper wants to educate others and bring awareness to the disease. She would also love to turn her HarperHandknit hats into a non-profit organization.

Harper has come a long way in her journey and thankfully it did not end for her at Ovarian Cancer. While it will always be a part of her, she views it as a blessing in disguise. Now she knows her purpose: *To live with love, get educated, know her body, and keep an open mind.*

To see Harper's hats and "Like" them on Facebook, go to www.facebook.com/pages/HarperHandknit/153138578180248

In the Spotlight

- On April 19th, Melissa Burke and her family hosted Mama Bear's Spring Fiesta to raise money for team t-shirts for our 2nd Annual Zoo Walk. Any additional monies raised beyond what was needed for the t-shirt fund was donated to The Belinda Sue Fund. Melissa lost her mother to Ovarian Cancer in 2005 and Melissa, herself, is a one-year survivor of the disease. The event was a huge success, and at The Belinda Sue Fund's gala on May 10th, Melissa and her family presented Tom Nantais with a check for \$2,250. So "Thank You" to the Mama Bear clan for their generosity & support!
- We were pleased to have guests of **Hour Detroit Magazine** attend The Belinda Sue Fund 2nd Annual Gala. Go to <http://www.hourdetroit.com/Hour-Detroit/May-2013/Belinda-Sue-Fund-2013-Gala/> to view the photos online. Photos will also appear in the **July issue of HOUR Detroit Magazine**.
- Keep an eye out for The Belinda Sue Fund billboard on Telegraph Road. It is located on the west side just north of 6 Mile Road and is facing south for northbound traffic to see.

Did You Know?

- The risks of Ovarian Cancer and Endometrial Cancer appear to be reduced with the use of oral contraceptives, whereas the risks of Breast, Cervical, and Liver Cancers appear to be increased.*
- Ovarian Cancer can invade, shed, or spread to other organs:
 - **Invade:** A malignant ovarian tumor can grow and invade organs next to the ovaries, such as the fallopian tubes and uterus.
 - **Shed:** Cancer cells can shed (break off) from the main ovarian tumor. Shedding into the abdomen may lead to new tumors forming on the surface of nearby organs and tissues. The doctor may call these seeds or implants.
 - **Spread:** Cancer cells can spread through the lymphatic system to lymph nodes in the pelvis, abdomen, and chest. Cancer cells may also spread through the bloodstream to organs such as the liver and lungs.*

*Facts taken from The National Cancer Institute (www.cancer.gov)

Getting Ready for Our 2nd Annual Zoo Walk!!

It seems like just yesterday we hosted our 1st Annual Zoo Walk! Well, September is just around the corner! This year the Zoo Walk will be held on September 8th, which is the Sunday following Labor Day weekend. We had such a huge turnout last year that this time around we anticipate the attendance to be even larger. We will have some great vendors and sponsors again this year, along with entertainment and goodies for everyone to enjoy. So while you're relaxing over the summer, be on the lookout for Save-the-Date cards to be mailed soon. Keep checking back on our website (www.belindasuefund.org) and our Facebook page (www.facebook.com/thebelindasuefund) for more information. We plan to have online registration open in July. We look forward to seeing everybody there. It is sure to be a great time where families and friends can enjoy a day at the Zoo while helping to support Ovarian Cancer Awareness & Research!

Make a Donation!

To make a tax-deductible donation, go to www.belindasuefund.org and click on the "Donate" tab

Save-the-Date!!

Event: 2nd Annual Zoo Walk

Sunday, 9/8/2013
Detroit Zoo in Royal Oak

Online registration opens July 2013

Event: Brunch with Santa

Saturday, 12/14/2013 at 11:00am
San Marino Club in Troy

Online registration opens Nov 2013

Event: 3rd Annual Gala

Saturday, 5/17/2014
The Henry in Dearborn

Invitations to be mailed and online registration to open Mar 2014



Tom Nantais & Keli Giannini



The Belinda Sue Fund Board Members



Tom Nantais & DeAnn Sturdivant

The Belinda Sue Fund's 2nd Annual Gala held on May 10, 2013
For more photos visit our website: www.belindasuefund.org