

HopeLine

connecting you to a network of support

Mission Statement

Hope for Two... The Pregnant with Cancer Network is an organization dedicated to providing women diagnosed with cancer while pregnant with information, support and hope.

Guiding Values

We serve women of all socioeconomic, ethnic and religious backgrounds worldwide. Volunteers with a history of cancer while pregnant are the mainstays of our support network. We strive to remove barriers to women obtaining complete and accurate information about their options for dealing with cancer while pregnant. We respect and support every woman's personal decisions without judgement.



Hope for two
the pregnant with cancer network

Message from the Chairwoman

Patty Murray...

Say anything other than, "It's probably an ingrown hair!"

My "How to" manual on what to say or not say to "sick" people



For starters, there are no perfect phrases or magic words to say to a "sick" person who is battling a medical or psychological condition. Quotation marks are around the word "sick" since I never considered myself to be ill the two times that I was diagnosed and treated for cancer. Rather, I was a human, like everyone else, who just happened to have a disease, for the time being.

This article has been twenty-two years in the making since that fateful day I went to my regularly scheduled OB visit for my pregnancy. I confided in a close family member that I was concerned about a golf ball sized lump that I found under my arm. She retorted, "It's probably an ingrown hair, don't worry!" A month later I was diagnosed with an advanced and aggressive form of breast cancer and immediately started treatment. I was in the fight of my life against a disease that was anything but an ingrown hair. Perhaps this person didn't know how to respond but it would have been better to remain silent.

What further maddened me was the way many people approached me, with their eyes and voices lowered, inquiring, "Just how *are* you doing?" If I wasn't depressed already, their hushed tones and defeated posture definitely pushed me in that general direction. What I wanted to do was to take them by their shoulders, shake them, gently of course, and tell them to stop it. More than anything, I wished for them to speak normally. To ask me how I was doing, maybe offer to help, to be there by my side, even if just for a short visit, and chat about everyday things like family activities, upcoming vacations, and the like. But I never said any of that. Rather, I found myself consoling those not afflicted with any disease.

Another faux pas was when people would say, "Me too," or "I know what you are going through because my _____ (insert friend, family member, etc.) went through that also!" Unfortunately, the focus then shifts off of the "sick" person when such statements, however well-intentioned they may be, are uttered. These tendencies must end. Every person is an individual and their disease is unique to them. Their diagnosis, treatment, support systems, family, and methods of handling it all are distinctive and should not be diminished by saying you know someone who had the same thing.

Another common occurrence that should be avoided is when the "sick" person becomes the cheerleader, when a friend or family member usually says, "Oh my goodness, it must be so difficult for you to deal with all of this! [...]"

See "CHAIRWOMAN'S MESSAGE" continued on page 4.

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my story

by Karla McAdam

real stories of women diagnosed with cancer during pregnancy

For many women, receiving the news of a pregnancy brings feelings of joy and excitement. Thoughts turn to eating well, resting, and building a new nursery. But in Karla's case, nothing could have prepared her for the news that would change those feelings.

During self-examination, Karla, 41, and a mother of one, discovered a lump in her groin. She made an appointment to have it checked out and after a biopsy was performed, doctors informed her that the results were inconclusive. Karla went about life. But the nagging feeling that the lump didn't seem normal persisted.

Karla decided to have a second opinion with the experts at Penn Medicine. What appeared to be a healthy, stress-free pregnancy would soon turn into a long journey of survival and recovery. Karla was diagnosed with Hodgkin's lymphoma, stage 1 *and* Non-Hodgkin's lymphoma, stage 1, follicular B3. The news was devastating but thankfully, Karla's dedicated team of obstetricians, maternal fetal medicine specialists, and oncologists sprang into action and developed a multidisciplinary treatment plan to treat the cancer and her baby all at once.

Facing two types of lymphomas, Karla's treatment needed to begin immediately in order to save her and her baby. Her first method of treatment was chemotherapy. While having lymphoma diagnosed during pregnancy is uncommon, many women have received chemotherapy for cancer during pregnancy. There is enough research that shows chemotherapy is safe beginning in the second trimester. The only concerning side effect Karla experienced was decreased movement of her baby following treatment. "Shortly after chemo,

I noticed my baby wouldn't move as much. I figured that whatever I felt, my baby felt. If I was tired, she was tired," says Karla.

The chemotherapy treatment worked. After delivering a healthy baby girl in February 2017, Karla was in remission. However, she had an aggressive type of cancer, prompting her team of doctors to begin radiation therapy two weeks later.

"FACING TWO TYPES OF LYMPHOMAS, KARLA'S TREATMENT NEEDED TO BEGIN IMMEDIATELY IN ORDER TO SAVE HER AND HER BABY."

Karla's newborn, Olivia, is a healthy, happy baby, who joined big brother Nico, 8. Daily life continues to be busy for Karla but that hasn't slowed her down. She is excited to be celebrating her recent marriage and, together with her husband Franklin, their newly blended family. Her oncologists have told her that there is a strong possibility that the cancer may return. She currently sees her doctors every three months and will more than likely continue follow up for the rest of her life. Although some fear of recurrence remains, Karla stays focused on good health and enjoying her family.

Karla is thankful for her amazing group of talented physicians who saved her life and her daughter's. She is grateful for *Hope for Two* and her encouraging support woman. Since her experience, Karla has been inspired to become a volunteer support woman herself to provide the same hope to others. ❧



Hope for Two member Karla McAdam.



Karla McAdam's daughter, Olivia.



Hope for Two member Karla McAdam with son, Nico.

ask the therapist

BY CHRISTINE BYLEWSKI, LCSW-R, BCD

Chris is a former Vice-Chairwoman of Hope for Two...The Pregnant with Cancer Network Board of Directors and a co-author of the Hope for Two Volunteer Support Woman Training DVD.

Q:

I seem to be surrounded by bad news, all the time. I am struggling with my health and pregnancy, hurricanes are destroying homes and killing people, people are rioting in the streets, etc. I feel I am drowning in negativity. What can I do to help myself?

A:

The first thing you can do is protect yourself from over exposure to the news. You can choose to ask your spouse/partner to inform you of something important rather than watching it firsthand. Tell your friends that you cannot listen to bad news now and ask that your conversations with them be about positive things. Start your morning with a "happy thought".

Examples: You are safe at home with your loved ones. The sun is shining. The leaves are starting to change and choose to notice the colors. Try to stay in YOUR moment. Find a word or phrase that helps you to be calm, like BREATHE, PEACE, COMFORT, I AM OK, I AM LOVED. With practice, you will find that these relatively simple techniques can help you make you feel better. ☺

If you live in the Western New York area and would like to serve on the Hope for Two Board of Directors, please contact Patty Murray at info@hopefortwo.org.

If you are receiving our newsletter by mail and wish to receive it electronically, or to unsubscribe, please contact us at info@hopefortwo.org.

Rocking with Hope for Two Fundraiser and 20th Anniversary Celebration

On April 27, 2017, over three hundred people attended Asbury Hall in Buffalo, NY to celebrate *Hope for Two's* 20th Anniversary. This highly successful event owes its thanks to our generous sponsors, especially the New Era Foundation, our donors, attendees, Board of Directors and, of course, our members.

Guests in attendance enjoyed a wonderful assortment of food from well-known Buffalo restaurants, including Hutch's, Tempo, and The Chocolate Bar. Dash's Food Market also provided delicious hors d'oeuvres and food stations. Guests were entertained by the fabulous music of the Michael Bly Band: Michael DiSanto and Ali Critelli.

This year, we had the pleasure of hearing from three wonderful speakers at our event. Our Co-founder and Chairwoman, Patty Murray, began the evening by introducing the first speakers of the night- two of her children, Molly Murray and Patrick Murray (the first *Hope for Two* baby), followed later by our member, Annette Hill. Annette was gracious enough to share her story of survival and the role that *Hope for Two* played as she faced cancer in pregnancy.

Thank you to everyone who helped make this fundraiser and celebration of 20 years of hopeful support so successful! ☺

New ways to support Hope for Two through AmazonSmile

We are excited to share that there are new ways to support *Hope for Two* when shopping at Amazon.com! Simply bookmark this link for eligible purchases to benefit *Hope for Two*: <http://smile.amazon.com/ch/16-1549731>. ☺

Donation from Canisius College's ENACTUS students

BUFFALO, NY—Canisius College ENACTUS Executive Board members voted to donate a percentage of their proceeds from one of their entrepreneurial programs, Quad Gear, to *Hope for Two* last October during Breast Cancer Awareness Month. They sent in a \$500 donation.

ENACTUS is a global non-profit and community of students, academic, and business leaders committed to using the power of entrepreneurial action to transform lives. We thank this small group of passionate business minded college students for giving back to our world by donating to *Hope for Two*. It is truly commendable and greatly appreciated. Patrick Murray, volunteer for *Hope for Two* and son of founder, Patty Murray, sits on the Executive Board for ENACTUS at Canisius College. ☺

Langer Family Donation



Special thanks to our member and volunteer support woman Mara Langer and her family, husband David and children Malia and Ari, for their recent generous donation. Mara was nominated by a friend to participate in the “Facebook Fundraising Challenge” and chose *Hope for Two* as her charitable cause. The family also held a garage sale where they designated a percentage of the proceeds to go to charitable giving (Tzedakah). Again they chose *Hope for Two* as their designated charity. Thank you to the entire Langer family! ☺

chairwoman's message continued...

How are you handling all the stress and fear? Then the “sick” one has to take on the role of the cheerleader and responds, “Oh don’t you worry, we’ll be done before you know it” and other empty rote phrases. When these situations happen, the “sick” person tends to feel as if she is in an alternative universe, where the afflicted is comforting the bystander. Comforting others, when the “sick” person should be the one comforted, happens all too often, unfortunately. It drains them of their already severely depleted mental and emotional resources. Please make sure to put the needs of the ill person first, then to seek out support networks for yourself later, if necessary.

Thus far, most of this article has been what not to do. So what do you say? Personally, I have always fallen back upon the Golden rule: “Do unto others as you would have them do unto you.” Matthew 7:12. Every culture and religion has a version of this rule and for obvious reasons. Simply put, offer help, lend an ear, or tell them you love them. The “sick” individual wants anything but pity. Encouragement, hope, support, assistance, cheerfulness, laughter, smiles, and hugs are, however, always welcome. If nothing comes to mind, stay silent. Your mere presence is a gift in and of itself.

Until next time, wishing all of us the ability to tap into our intuition in order to say and do the “right” thing the next time we encounter a fellow human being in need of compassion, assistance, and understanding. We all stand to benefit from this renewed approach. ☺



Hope for Two member Karen Cleary's daughter, Giuliana.

Special Deliveries

babies born to mothers

who were pregnant with cancer

☞ DONA EMMANUEL gave birth to Janae in December 2015 (6 lbs. 8 oz.)

☞ TIFFANY GREEN gave birth to Sanaa Janai in October 2016 (4 lbs. 1 oz.)

☞ KIRSTEN CHAPMAN gave birth to Bryce Richard in February 2017 (7 lbs. 5 oz.)

☞ KARLA MCADAM gave birth to Olivia in February 2017 (5 lbs. 2 oz.)

☞ KHIM OWENS-BAGGETT gave birth to Yuri Zane in April 2017 (6 lbs.)

☞ KAREN CLEARY gave birth to Giuliana Grace in August 2017 (7 lbs. 13 oz.)



Hope for Two member Khim Owens-Baggett with daughter, Yuri.



Hope for Two member Tiffany Green's daughter, Sanaa.



Hope for Two member Kirsten Chapman with son, Bryce.

*tell us about
your little miracle*
info@hopefortwo.org

Cancer and Pregnancy Registry: Latest Updates Regarding Taxane Use in Breast and Ovarian Cancer Treatment

BY ELYCE CARDONICK, MD, FACOG

The combination regimen of doxorubicin and cyclophosphamide, with or without 5-FU, has been used to treat breast cancer during the second and third trimesters with a relatively safe toxicity profile for mother and fetus. In the majority of cases, taxanes such as paclitaxel or docetaxel have been delayed until after delivery based on the small number of cases published. The addition of taxanes to an anthracycline based regimen in non-pregnant women however has resulted in a statistically significant reduction in the risk of relapse (17% relative reduction) and death (15% relative reduction) for high-risk breast cancer patients. This disease-free survival (DFS) benefit was shown to be independent of ER expression, degree of nodal involvement and type of taxane. The priority of the Cancer and Pregnancy Registry is to treat the pregnant cancer patient as similarly as possible to the non-pregnant cancer patient while balancing fetal risks. It was discovered that the human placenta secretes a protein called P-glycoprotein that works to send medications such as taxanes away from the fetus. It appeared that a theoretical risk to the fetus was outweighed by the benefit to the mother. As I always say, the best way to have a healthy baby is for the mother herself to remain healthy. For patients who complete anthracycline-based therapy for breast cancer before 28-week gestation, before considering a preterm birth in order to start taxanes as soon as possible after delivery, consideration can be given to receiving taxanes during pregnancy and delaying the birth.

Still there was little data regarding the safety of taxane use for breast or ovarian cancer during pregnancy. In 2012, a paper was published regarding 16 fetuses treated with taxanes during pregnancy reported to the Cancer and Pregnancy

Registry. Birthweights were significantly low in 18% of infants but without long term sequela. We could not find any statistical difference in the incidence of growth restriction when compared with neonates exposed to chemotherapy not including taxanes.

To date, 53 women enrolled in the Cancer and Pregnancy Registry have received taxane therapy during the second and third trimesters of pregnancy. Twenty of these children are older than 18 months of age and have participated in the developmental testing study. Their results will be compared to children whose mothers received only anthracycline based therapy and delayed taxane treatment until after delivery. Stay tuned to see the results of this analysis. As always the risk of a preterm birth with postpartum taxane treatment needs to be balanced against exposure during pregnancy. When performing developmental testing on children exposed to chemotherapy in utero in two simultaneously performed studies, the children demonstrating developmental delays were concentrated in the groups delivered preterm.

The Cancer and Pregnancy Registry continues to collect cases of women diagnosed with any type of cancer diagnosed during pregnancy. Women are followed from the time of the cancer diagnosis, through treatment plans and pregnancy outcomes. What is unique about the Registry is that close follow up doesn't end when the pregnancy does, rather the woman and her child are followed yearly to document any health developments for the child and for the benefit of newly diagnosed women who face difficult choices. Even if termination of pregnancy is the necessary choice for a couple, or the patient suffers a miscarriage, the woman can still be followed yearly. To date, 364 women are enrolled in the Can-

cer and Pregnancy Registry, 222 of whom received chemotherapy during pregnancy. All information is kept confidential

There is power in numbers, and knowledge gained from pooling different cases internationally. No one hospital, oncology or obstetric practice will see enough pregnant women with cancer to appreciate similarities, differences and outcomes among women with cancer in pregnancy.



Dr. Elyce Cardonick, an active member of Hope for Two's Board of Advisors, is a Maternal Fetal Medicine specialist, who created and is the Director of The Cancer and Pregnancy Registry. This international registry tracks the pregnancy outcomes and long term health of women and children of women diagnosed with cancer during pregnancy. This beneficial tool helps these women make difficult choices based on data and facts, not fear. Each new patient that participates in the Registry contributes to not only helping themselves, but also provides critical data to help women worldwide make educated decisions. Additionally, Dr. Cardonick is available to work with a woman's oncologist in deciding which tests and procedures can be performed, and when, during pregnancy to maximize the safety of the unborn baby while not compromising the chance of cure of the mother.

Dr. Cardonick may be reached for details about participating in the Registry at www.cancerandpregnancy.com, by calling 1.877.635.4499 (toll free) or 1.856.342.2065 (please note, this number has recently changed). Follow the Registry on Instagram @cancerandpregnancyregistry.



Hope for Two member Dona Emmanuel with daughter, Janae.

Pregnancy Registry for Herceptin, Perjeta and Kadcyla

The MotHER Pregnancy Registry is an observational study to determine the safety of Herceptin® (trastuzumab), Perjeta® (pertuzumab) or Kadcyla® (ado-trastuzumab emtansine) in women and their babies when trastuzumab, pertuzumab in combination with trastuzumab, or ado-trastuzumab emtansine therapy is used within 7 months prior to or during pregnancy. The Registry is sponsored by Genentech, the company that manufactures Herceptin®, Perjeta® and Kadcyla®.

The MotHER Pregnancy Registry collects data from women and their doctors about the women's breast cancer status and treatment (oncologist), their pregnancy (obstetrician/maternity care provider) and their newborn baby's care provider/pediatrician for 12 months after delivery. There are no additional office visits, tests or medications required, and there is no cost to participate in the Registry.

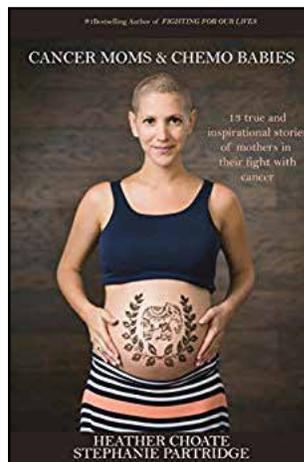
Participation in the MotHER Pregnancy Registry is voluntary; eligible women provide consent and medical releases for themselves and their infants. All medical information collected during participation in the Registry is considered confidential and all data that are analyzed or published is kept anonymous. In other words, women participating in the Registry and their babies will not be identified by name or other personally identifying information.

Your participation in the registry may help understand the safety risks of using Perjeta®, Herceptin® or Kadcyla® during pregnancy and minimize the risk for pregnant women and their babies in the future. If you want to know more and how to participate, please visit: www.motherpregnancyregistry.com. ❧

book review

Cancer Moms and Chemo Babies

BY HEATHER CHOATE AND STEPHANIE PARTRIDGE



The excitement and anticipation of holding the sweet, small baby, feeling those first kicks on the belly, and wanting the best for him or her all while fighting a war within that begets destruction.

In this nonfiction collection of stories written by thirteen pregnant women with cancer, they face two divine milestones: life and death. Labeled a miracle and a vision of hope and endurance of humanity, their stories have been shared in numerous

social media articles and viral photographs, ten different news reports on NBC, ABC, CBS, and Fox news, the Today show, local magazines and news stations, a national ad campaign by the American Cancer Society, People magazine, Wall Street Journal, a New York Times article, an LBBC brochure, blogs, Amazon Bestseller awarded *Fighting For Our Lives; A Memoir*, local newspapers, radio, and a Yahoo feature article.

Each of their voices are unique and in each chapter we see a glimpse into their journey with cancer and motherhood. *Our Story: Cancer Moms and Chemo Babies* digs deep into their fears, their hopes, their wisdom, and their unconventional friendship through motherhood and cancer. ❧

Cancer Moms and Chemo Babies is available for purchase at Amazon.com, Barnes & Noble and other online retailers.

To view other books reviewed by Hope for Two, visit our website: <http://www.hopefortwo.org/category/book-corner/>

testimonial

“Thank you so much for connecting me with [support woman] Melissa - our conversations thus far have been invaluable to me and incredibly helpful as I go through this tough journey.”

AMY P., NEW JERSEY

www.hopelfortwo.org

Hopeline is printed to share ideas and stories among members. If you'd like to share your story, birth announcement or information for publication, please contact us!

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FIND US ON FACEBOOK!

Materials published in Hopeline are not intended to provide medical advice, which should be obtained from a qualified physician. Information and ideas included do not necessarily reflect the views and opinions of all members.

The Hopeline newsletter is produced by Hope for Two member Jodie Orzechowski. Jodie dedicates her time to the newsletter because the photos and stories are inspiring and comforting. The newsletter is a way for her to pay it forward.

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