Got News?

www.hopefortwo.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!

INFO@HOPEFORTWO.ORG

1.800.743.4471

Hope for Two...The Pregnant
With Cancer Network
PO Box 253
Amherst, NY 14226

FIND US ON FACEBOOK!

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Hope for two
the pregnant with cancer network

Hopeline

connecting you to a network of support

Mission Statement

Hope for Two... The Pregnancy 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 world-wide. 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 . . . Never Give Up

Despite the odds, NEVER GIVE UP! 22 years ago, weeks into our infancy, as Development Director, I contacted every major cancer center in the United States and Ontario, Canada, informing them of our existence and services. Many were very encouraging and put us in their Rolodexes, but surprisingly, a respected New York center informed me, "contact us in two years. Maybe, after that, we might refer patients to you, as most small non-profit support groups have a mortality rate of two years." Wasn't that such a supportive and sensitive thing to say, from a cancer center, whose mission was to treat and support cancer patients, to a cancer survivor who wanted to help pregnant women with cancer? Undiscouraged, we forged on.

Along the way, we have faced many such naysayers and obstacles. In 2002, when the Patient Coordinator position was shared amongst our "working" (i.e., volunteering) Board of Directors, we conceived of creating a virtual office-a database, where anyone, with authorization, anywhere, could perform the duties of the position, match patients, and even send thank you letters electronically. Many IT professionals informed us that such a database did not exist that would fit our needs. However, due to a prior work experience at my Dad's State Farm Agent's office, I knew that it could be done. If one did not exist, we could create one. We recently invested in upgrading to a Support Database which is more manageable, efficient, and up to code. It will serve us years into the future. We knew it could be done!

At the same time in 2002, we were experiencing Board member burnout and a couple of resignations, since we were such a small working board, with no part-time employees. Without notice, a ranking Board member convinced many other members to "fold up" and give whatever we just raised at our first fundraiser to our local cancer center. My inner voice told me that this was sheer lunacy since so many needed our services, not just in the Western New York area. Finally, after solid persuasion, most Board members agreed with me. We didn't fold. We didn't give up!

I have used these lessons learned about sheer focus of conviction and on positive outcomes in other areas of my life and have passed them on. Every day, legions are faced with daunting health concerns and dire statistics, fears that the cancer might recur, fear of their mortality, fear that this regimen might not be effective, fear of not making the right decision, etc. My advice is always to look within, believe in yourself and your wisdom, look to others for help, "think outside the box," or encourage your medical professionals to do so, and always keep the faith!

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Patty Murray . . . Never Give Up (continued from page 1)

We have believed in ourselves. We have been so blessed by our generous donors and dedicated Board of Directors, who have enabled us to stay true to our mission, and to hire part-time employees as compassionate and competent as the founding members. To highlight the dedication and passion of those here at Hope for Two, I'd like to share with you a report from our newest Patient Coordinator (PC), Juli Morlock, who has worked for us part-time since November 2017, while also holding down a full-time job. The PC is the heart and soul of what we do at Hope for Two. Before our February 2019 Board meeting, I asked her to give a brief report on her past year with us. It follows right after this Chairwoman's message. Please read it in its entirety. *You won't regret it.*

We've kept the faith for 22 years and our mission to help more women in need is stronger than ever before. In April 2019, we connected nine women; in May 2019, 15 women; and we are slated to help even more in June and July. Our numbers are growing- we didn't fold! Until next time, "NEVER GIVE UP!"

Message from the Patient Coordinator - Juli Morlock

Over the past year, since joining Hope for Two, I have been trying to really jump in and take over as best as I can. I work hard to match the most appropriate support woman to our new members.

I have witnessed first hand this much needed, and valuable, support system. I am amazed to see how much assistance, hope and friendship it brings throughout these women's difficult journeys. In the last several months I have been working to reach out and certify more volunteer support women, without them we could not carry out this important mission of hope.

In addition to this, I have also been working closely with Patrick to assist with the women he connects with on our social media sites. This has made a HUGE impact in helping aid more women across the world by either connecting them with our support women, certifying more support women, helping them with loss, or just by reading our stories of hope to see that they too can have healthy outcomes. These women feel very alone until they find us and finding out they are not, means everything to them.

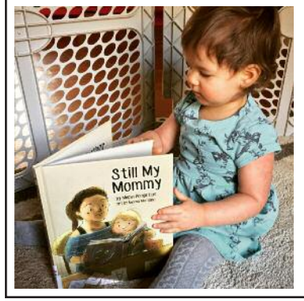
I had a woman reach out to me that we previously connected with to tell us how very thankful she was to have this support at a very scary time. Thankfully her scare was not cancer but she still could not say enough positive things about her support woman and our organization for being there for her.

This last year has brought many stories of aspiration and friendship. I have had several women reach out to say that they are traveling to meet their support woman and that they plan on becoming lifelong friends. One support woman in the US is traveling to Mexico just to meet the new member she assisted. They all truly appreciate our support network and have found new friends and dreams of hope.

I have to be honest, I was not sure about joining Hope for Two and was worried it would have been too hard to keep up, while also working a full time job. After being here for over a year I can most definitely say, I am both thankful and honored to be a part of this very important and valuable support network. I cannot imagine my life without being able to connect these women and do whatever I can to provide such a message of HOPE!!

Thank you all, especially to Patty, Mary Rose and Lisa for founding this organization. Also HUGE thanks to Patrick for running our social media as it has helped tremendously in supporting women that in this day in age are on social media daily.

Book Review



In 2013, Megan Pomputius received an ovarian cancer diagnosis while raising her two year old daughter. Her diagnosis and treatment led to many questions from her child, motivating Megan to write a children's book to help other mothers and families facing similar circumstances. Written from the child's point of view, Still My Mommy is a helpful resource for families to assist young children in understanding that even though many physical changes may occur during a mother's illness and treatment, she remains the same person. An easy read, reassuringly addressing common concerns faced by many families coping with this experience. Thoughtfully illustrated by Andrea Alemanno.

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

How To Apply For Social Security Disability Benefits With Cancer

If you have been diagnosed with cancer and you are unable to work because of the symptoms of the disease or the side effects of the treatment, you might be able to qualify for Social Security Disability benefits. The approval process can be fast and straightforward or it can take a little while and require you to file an appeal after your claim has been denied. The process will revolve around your specific kind of cancer, its stage, the prognosis, and the treatment plan and how you are affected by the treatments and by the cancer symptoms.

Getting Approved For Disability Benefits With Cancer

As a Compassionate Allowance: There are some cancers that will be quickly approved for disability benefits. The SSA has a Compassionate Allowances Program (CAP) that has a list of medical conditions, many of which are life-threatening, that will result in the expedited approval of the claimant for disability benefits. Instead of having to wait up to a year for a hearing before an administrative law judge after filing an appeal, if you show definitive medical proof of being diagnosed with one of these conditions, you can be approved for disability benefits in as few as a few weeks.

The Compassionate Allowances List (CAL) includes more than 50 different kinds of cancer. Besides being included on the CAL, your cancer must be inoperable, unresectable, recurring, and have distant metastases, which means it must have spread to distant body parts. As an example, if you have stomach cancer, and you have medical tests to prove the diagnosis, and then your medical records clearly show that your stomach cancer is unresectable, inoperable, has recurred after treatment, or has spread to distant areas of the body, your claim will be expedited by Disability Determination Services (DDS) using the CAP.

Via the Blue Book

If you don't meet the criteria for CAP, you can still qualify for disability with a cancer diagnosis if it meets the medical criteria included in the Blue Book, which is the SSA medical guide. That means that if your cancer is metastasized, inoperable, recurrent, or unresectable, and your medical records clearly state that, then you can be approved. Cancer is listed in the Blue Book under Section 13.00, which is used to evaluate all adult cancers except some cancers that are associated with HIV infection. When the cancer is being evaluated, DDS will determine the origin of the cancer, the extent of the cancer's involvement or how far it has spread, the effects of any post-therapeutic residuals, and the duration, frequency, and response to cancer treatments, such as surgery, radiation, or chemotherapy.

Via Medical Vocational Allowance

If you're cancer diagnosis isn't on the Compassionate Allowances list or meet the Blue Book listing, you may still be able to qualify for disability benefits through a medical vocational allowance. If your treatments are expected to keep you from working for at least 12 months, consider having your doctor fill out a Residual Functional Capacity (RFC) form on your behalf. This form will state that you are medically unable to work within your specific skill set.

Your Family May Receive Auxiliary Benefits

If you are approved for disability benefits, then your family members, including your dependent children and your spouse, may qualify for auxiliary benefits from your account. This is only true if you receive Social Security Disability Insurance (SSDI) and doesn't apply to Supplemental Security Income (SSI), which is needs-based. To qualify for auxiliary benefits, specific criteria must be met. Your spouse must be younger than 62 and a joint caregiver of any children younger than 16. For your children to qualify, they must be your dependent, younger than 18 or enrolled in school full-time, and unmarried. Those who receive auxiliary benefits can receive up to 50% of your monthly disability payment amount. There is a household maximum, so your dependents may not always receive less than 50%.

Applying For Disability Benefits

To apply for disability benefits, there are a number of ways. You can apply online any time. You are able to save the application to work on before submitting. If you prefer to apply in person with the help of an SSA representative, you can make an appointment at your local SSA office to apply. Simply call 1-800-772-1213 ahead of time to reserve your spot. Once you are approved, the benefits can be used to help pay for any daily living needs!

HELPFUL LINKS

Compassionate Allowance List:
https://www.ssa.gov/compassionateallowances/

Blue Book Section 13.00:
https://www.ssa.gov/disability/professionals/bluebook/13.00-NeoplasticDiseases-Malignant Adult.htm

Applying with Cancer:
https://www.disabilitybenefitscenter.org/social-security-disabling-conditions/cancer

RFC Form:
https://secure.ssa.gov/apps10/poms/images/SSA4/G-SSA-4734-U8-1.pdf

Auxiliary Benefits:
https://www.ssa.gov/planners/disability/family.html

Online Application:
https://secure.ssa.gov/iClaim/dib

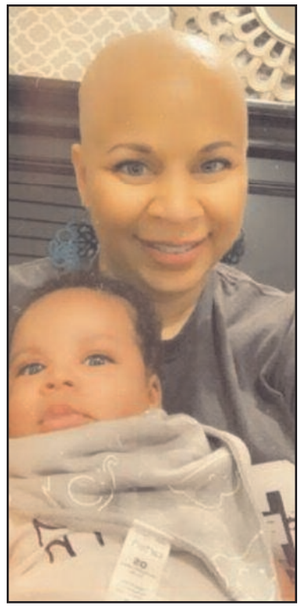
SSA Offices:
https://www.disabilitybenefitscenter.org/state-social-security-disability

Special Deliveries . . .

babies born to mothers who were pregnant with cancer

Jocelyn Limmer gave birth to Charlotte Rae (2 lbs, 9oz) in November 2018

Grace Pingil gave birth to Emmanuel Gavin Escobar (6lbs, 4 oz) in December 2018.



Tamara Satterfield gave birth to Teague (5 lbs, 1 oz) in December 2018.

Kimberly Abreu gave birth to her baby girl (6 lbs, 5 oz) in December 2018.

Breanne Schreffler gave birth to Cayzlee Elizabeth (6lbs 11oz) in January 2019.

Leah Stufflebum gave birth to David Wendell Stufflebam (6 lbs 11 oz) in January 2019.

Tell us about your little miracle info@hopefortwo.org

my story

by Khim Owens-Baggett

I found a lump myself in the shower one day, in 2016. I think I was shaving my armpit. It was right where my new underwire bra stopped, so I just figured it was an irritation from that. I went in and told my Ob-Gyn about it, and she said, "Let's go ahead and do the mammogram." They found invasive ductal carcinoma, estrogen-positive.

The treatment plan was really simple - a lumpectomy and then [estrogen-blocking drug] tamoxifen for however many years, so no chemo, no radiation. I thought I was getting off easy. But when it came time to look at the pathology results after the lumpectomy, the doctor said it was completely different from what they had seen on the imaging, and that I might want to consider a mastectomy, and that we should start the tamoxifen right away, and that I'd need birth control because you can't get pregnant on the drug.

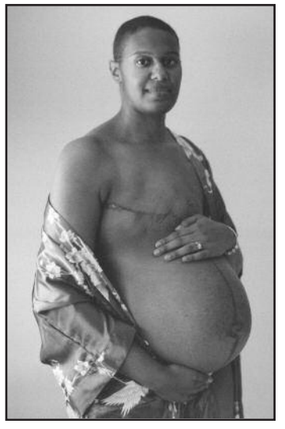
I went to my Ob-Gyn again for birth control, and we did a pregnancy test. She was like, "Um yeah, you're pregnant, honey."

I was not quite two weeks pregnant when I had the lumpectomy, and they missed it.

When I got the diagnosis for cancer I was like, "This is 2016, there's lots of trials and stuff out here, it's going to be fine, I'm going to kick butt." When they were like, "'You're pregnant,' that's when I couldn't wrap my head around it. I was like, for real? I was not familiar with people having cancer and being pregnant - like, was that something that was done? Are they going to tell me to terminate? Which they did. My Ob-Gyn said, "Your oncology team will tell you to terminate," and she wrote the [abortion] prescription. I just didn't fill it.

I found another doctor, who was supportive of my keeping the baby, saying, "This is your decision, and we'll do everything possible to make sure you're both safe and healthy."

I just wanted some kind of sign that everything was going to be OK. And when I heard that heartbeat on the monitor at the Ob-Gyn's office, I thought: Maybe this is my sign that I asked for. That's when I went home and researched and found the organization Hope for Two, which has been following [pregnant] women with cancer for the last 20 years or so. And I decided I would keep the baby.



Turns out they didn't get everything out of my right breast with the lumpectomy. I suggested a mastectomy - a double, the left as prevention - because you can do that while you're pregnant. I did that when I was solidly into the first trimester, and that was really hard. I breastfed my first two children, who were 7 and 3 at this time. But then I was like, well, I don't have to breastfeed this one, and I don't have to even worry about being mom-shamed for it!

But then after [my daughter was born and] they weighed her and laid her on my chest I felt, like, "Ugh. This is different." She was rooting right away and there was nothing there. It was kind of sad, even though I had already done it twice [with my older children]. Of course, at the hospital, every time the nurses came around, they'd ask, "Breastfeeding or formula?" and I was like, "I don't have breasts! Stop asking me!"

After the mastectomy, they found a suspicious lymph node and suggested going ahead with chemo and then radiation. I started chemo - there's only one regimen you can do when you're pregnant, doxorubicin - with four infusions every three weeks.

My husband and I didn't talk a whole lot about it all. It was more like, "OK, I have an appointment today…" When we told my kids that I was getting the mastectomy, my 7 year-old handled it pretty well, and for my 3-year-old, it was way over her head. We talked about me losing my hair, and they were so sweet when I finally shaved my head. My daughter said I was still a beautiful princess. They were very uplifting and encouraging. I did my best to try to continue doing normal things to the best of my ability.

That [pregnancy photo, above] was actually a week before I was induced. I was about to pop for real. Some of my co-workers asked if I was going to do a maternity shoot, and I said, "I don't think so… That's going to be a really awkward maternity picture." Then they paid for me to have a family photo session. The photographer said, "I don't know how you feel about a photo with full-on exposed scars and your belly" . . . and I was like, "Nope."

But then she sent me a few examples of women who had taken the photos, with their scars. I just felt how empowered those pictures made me feel, and I felt like it was such a rare occurrence to be pregnant and have cancer, because you don't hear about it all the time. And I knew that's all I wanted - to find others who were going through or had gone through

what I was going through - so I thought, you know what? I'm going to do this, because there's probably somebody out there in the same situation who that picture could help. And she did such a beautiful job.

I just did [breast] reconstruction in May. I opted to do the "DIEP flap," where they sort of cut out your midsection and cinch it back together, so I have a scar from hip to hip. They were like, "This is your chance to keep the baby pooch after you have the baby!" [Laughs] Then they use that skin and your belly fat to make into breast mounds. I call them my "Franken-boobs." There are some days when I think it's the ugliest thing I've ever seen in my entire life, and other days when I think it's so much nicer than having to put on a prosthesis, because living in Florida we obviously go to the beach, and I didn't want to do extra shopping for swimsuits that require the extra pockets and that kind of jazz.

The recovery actually wasn't too bad, but you have about six weeks where you can't lift anything or put your arms over your head. Sleeping was miserable, and I couldn't pick up the baby, so that was rough.

My biggest message to others is: Be your own advocate. Do your research. Find out what's being done for your cancer, check lots of hospitals, don't be afraid to get a second opinion, and find a support group. If you're under 40 with cancer, they have groups for that. If you're pregnant with cancer, they have groups for that.

I know what a difference it made to me to have spoken with someone who had gone through the exact same thing I was getting ready to go through and was fine - and I got to hear the baby in the background as she was telling me about her experience. It gave me a lot of hope and encouraged me on the hard days. I thought: OK, this stinks right now . . .

But when all is said and done, everything's going to be fine. And I'm going to have a happy, healthy baby to celebrate.

Save the Date!

Please join us on Thursday, November 7, 2019 5:30-10:00 pm. Hope for Two…The Pregnant with Cancer Network invites you to a Celebration of Hope for Two: Then and Now at Babeville's Asbury Hall, 341 Delaware Avenue, Buffalo, NY. We will be commemorating our 22nd year by looking back at the women whom Hope for Two has supported over the years and celebrating how far they – and their children – have come. Please consider sponsoring Celebration of Hope for Two: Then and Now by making a tax-deductible donation to our organization, purchasing event tickets or donating an item for the silent auction. Your sponsorship will help us continue to provide essential information and support through our peer to peer counseling services to pregnant women who are given the devastating diagnosis of cancer. All donations will be used for the sole purpose and benefit of patients and their families. Please look for more details about tickets and sponsorships on our website in the coming weeks- www.hopefortwo.org. We expect over 300 guests and friends will join us as we rock to some of WNY's favorite live artists. ***This event is open to the public and all are welcome!***

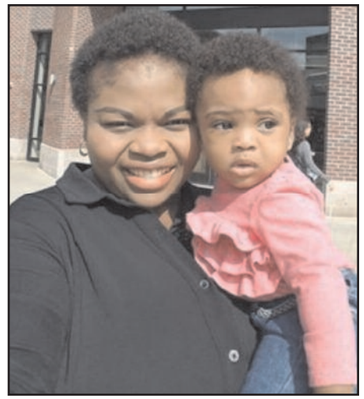
https://www.hopefortwo.org/celebration-for-hope-for-two-then-and-now/

Special Deliveries . . .

babies born to mothers who were pregnant with cancer

Tamara Ay gave birth to Musa Azim in May 2017.

Nicole Soto gave birth to Skyla Kaylani (4lbs 13 oz) in January 2018.



Silver Chikwado Barber gave birth to Rose Amara (9 lbs) in April 2018.

Robin Reader gave birth to Royal Robin (6 lbs, 3 oz) in June 2018.

Amanda Price gave birth to Annabelle Marie (1 lb 14oz) in July 2018

Lauren Perfors gave birth to Adelyn Ann (5 lb, 1oz) in August 2018.

Abigail Valletta gave birth to Madelyn in September 2018

Rebecca Arrington gave birth to Samuel Ethan (5lbs 14oz) in September 2018.

LaNell Jones gave birth Christopher Riggs "CJ" (7 lbs, 13 oz) in October 2018.