

# MAGEE

SPRING 2016

A PUBLICATION OF MAGEE-WOMENS RESEARCH INSTITUTE & FOUNDATION

A smiling woman with long brown hair is sitting on a blue couch, holding two young babies. Both babies are wearing matching light pink dresses with a floral pattern and a large pink ribbon around their waists. The woman is looking directly at the camera with a warm smile. The background is softly blurred, showing what appears to be a dining table and chairs.

**GIVING MORE WOMEN HOPE:**  
One recovery story with two  
very happy endings.

**THE PREGNANCY  
RECOVERY CENTER.**

A new way to help pregnant  
women with addiction.

**BREAST CANCER CARE AS  
INDIVIDUAL AS EVERY WOMAN.**

An innovative clinic with a new approach  
to comprehensive care.

**RESEARCH DISCOVERY:**

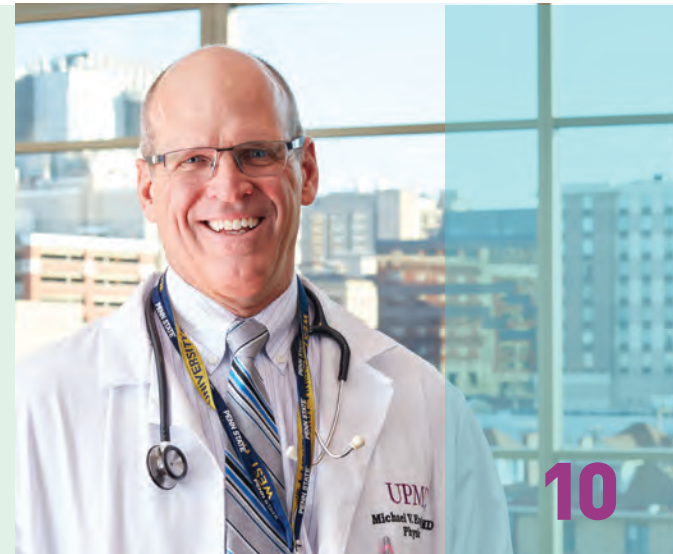
Breast Cancer Survivors Make  
Excellent Advocates for Clinical Trials.



# MAGEE

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# BREAST CANCER CARE AS INDIVIDUAL AS EVERY WOMAN.

AN INNOVATIVE CLINIC WITH A NEW APPROACH  
TO COMPREHENSIVE CARE.



Dr. Emilia Diego

Heather Durcho was 25 years old and excited about starting a brand new job and a new career. But right before she was due to begin work, she received the news that she had breast cancer.

"When I heard that I had breast cancer, it was scary enough," Durcho remembers. "But when I started to think about juggling everything else in my life, it really felt overwhelming."

However, Durcho had a new resource to balance her busy life and new diagnosis: The Breast Cancer Specialty Care Clinic at Magee-Womens Hospital of UPMC. The "one-stop" feature of this Clinic enabled Heather to keep moving forward with her life, her career and her treatment. "My day at the Clinic wasn't the most fun day I've ever had, obviously. But it was really nice that it was only one day when my husband and I had to take off work. The appointments weren't scattered all over the place at different locations and weeks apart."

Out of every 100,000 women diagnosed with breast cancer, 200 of them will be under the age of 50. And while that number may sound small, the repercussions can be quite significant. "It's often a more aggressive type of cancer in premenopausal women," says Judy Herstine, Program Administrator for Women's Cancer Services at Magee. "Every woman under the age of 45 who's been diagnosed with breast cancer should have genetic counseling and determine if they need genetic testing. The younger you are with breast cancer, the more risk there might be that it's genetic. That has implications for the patient's treatment and also for her family."

Being diagnosed at a young age comes with other challenges, as well.

"These women are diagnosed at a stage when they are extremely productive in society," says Dr. Emilia Diego, Director of the Premenopausal Breast Cancer Program at Magee. "They are mothers and wives. They are in the work force. They are friends, sisters, and an integral part of society. Maybe they just got a promotion or a new job. How are you going to tell your boss you're going to take time off to get cancer treatment when you're trying to climb that corporate ladder? How do you tell your kids about your diagnosis? These are all issues that can be psychologically distressing. The demographic is such that, because of their disease, there will be a lot of considerations that may not be quite as apparent in older patients, including the loss of work and the loss of time that they contribute to their family life."



**“We’d been working with the Glimmer of Hope Foundation for a number of years,” says Herstine, “The Breast Cancer Specialty Care Clinic is just one of the aspects of what they’re doing. We couldn’t have done the pilot and invested the resources and physician time if Glimmer of Hope hadn’t given us funding.”**

**-Judy Herstine, Program Administrator for Women’s Care Services at Magee**

All of this impacts the way treatment is given and the kind of support these young women need. For instance, if a woman is diagnosed during the childbearing age, reproductive fertility comes under consideration. Chemotherapy can affect fertility and women may opt to have their eggs harvested before starting treatment.

Plus, finding health care professionals who understand the impact of a diagnosis on the family is crucial to patients. “We call women who overcome breast cancer ‘survivors.’ But family members have survived the whole treatment process as well. So we designate them with the term ‘co-vivors,’” says Diego. “There is a psychological impact, not only on the patient, but on everyone who satellites around that patient.”

#### **A Glimmer of Hope. And the creation of a new clinic.**

In order to better meet the needs of these young women and their families, Magee created the Breast Cancer Specialty Care Clinic with funding from Glimmer of Hope, a Pittsburgh organization dedicated to supporting young women with breast cancer. Glimmer of Hope Founder and Executive Director Diana Napper was personally affected when a close friend died of breast cancer. She has made it her mission to create clinics such as this. “Young women have different concerns and needs,” says Ms. Napper. “They’re balancing more everyday living with a devastating illness. We find it to be a whole different disease when it strikes someone who’s premenopausal. There might be one or two other clinics in the country like this one. So for Pittsburgh to offer this – it’s impressive.”

Through a line of jewelry that Napper herself designed, and through meet-and-greet fundraisers with high profile Steelers such as Heath Miller, Brett Keisel, Alan Faneca and their wives, Glimmer of Hope has raised \$3 million since it started in 1994. Napper feels her organization is successful because people in Pittsburgh like to see that their money impacts the community they live in. “We show people that maybe one day one of their family members will benefit from these programs – and live.” So far, Glimmer of Hope has given \$1.8 million to Magee. \$137,000 of that went to start the pilot program for the Breast Cancer Specialty Care Clinic in November 2014, along with continued support for cancer genetics and patient navigation services.

“We’d been working with the Glimmer of Hope Foundation for a number of years,” says Herstine, “The Breast Cancer Specialty Care Clinic is just one of the aspects of what they’re doing. We couldn’t have done the pilot and invested the resources and physician time if Glimmer of Hope hadn’t given us funding.”

Herstine adds, “With them, we pulled together a focus group of young women who had breast cancer. We talked to the women about their experience and what they thought would make it better. We got their opinions about what we should do and shouldn’t do with a clinic. From that point, we started a pilot

program. After a year, we officially started the Breast Cancer Specialty Care Clinic.”

#### **How the Clinic works. And works well.**

“Our mission is to be able to pull all the resources together to make it more efficient and comprehensive for our patients,” says Herstine. “We’ve designed this clinic so that they can get quick access to a genetic counselor and to testing if that’s needed. We have surgical consultation with plastic and reconstructive surgeons. We have reproductive endocrinologists and infertility specialists, medical oncologists, radiation oncologists, clinical trials, and patient navigators. The Clinic is designed so that it’s almost a one-stop approach where you can get all those consultations done in one day. All those experts sit together and develop a plan of care for that patient, so when the patient leaves the Clinic that day she knows if she’s going to have radiation oncology and where it’s going to be. She knows if she’s going to have plastic surgery. She knows if she’s going to have chemotherapy. She has all this done at once, as opposed to having to go to different specialists at different days.”

Dr. Diego adds, “At at day in the Clinic, they will see the specialists that will be involved in their care. On average, most patients see at least five practitioners. That’s five times they would have had to get out of work and drive to a hospital – days of lost productivity for the patient and their companions to the appointment.”

Access to clinical trials is another reason why the Clinic is so important. “One of the members of the team is a clinical research coordinator,” Diego says. “So when the case is being discussed and the multi-disciplines are talking about the best treatment plan, we are also consciously exploring whether or not these patients are eligible for any clinical trials that we have open at Magee.”

Currently, the Breast Cancer Specialty Care Clinic is open every first and third Friday of the month. Appointments are scheduled so patients can meet with everyone they need to see in one day. “Clearly, most patients find it overwhelming to get a lot of information from several providers,” says Diego. “But it’s very beneficial. They get all the information in one setting, and most are satisfied that they are going home with a plan. The psychological impact of having to deal with something that’s scary and unknown is far more difficult than having to deal with something scary when there is a plan in place. It makes the process easier to get through.”

Since the Clinic was initiated in 2014, it has offered 16 clinic dates, seeing about four patients per day. “We’ve managed to serve 55 women in this setting. I’m hoping to ramp that up,” states Diego. “On average at Magee, we see about 1,200 breast cancer patients a year. Three hundred of those patients, or about 20%, will be under the age of 50. That’s another 250 women we could be serving.”



Diego goes on to explain why the number of young women with breast cancer coming to Magee is so high. "Magee is a tertiary care clinic. We are well known in cancer care and are a big referral center, not just in the region but also across the country. Patients who find themselves in these special situations seek special care, and Magee is able to deliver that."

Herstine adds, "Because we're a women's hospital, we have the reproductive endocrinology and infertility specialists right here, which other places don't have. We have cancer genetic specialists here, too. And because of our relationship with the Women's Cancer Research Center, we have the research here, as well. We have an extensive patient navigation service, dedicated specialists in breast imaging, breast surgery, plastic and reconstructive surgery, medical oncology, and radiation oncology. Our medical oncologists and breast surgeons spend all of their time doing breast cancer work, so that's very focused."

#### Hope for the future.

"If these programs are successful and we see patient results improving because their care was tailored for them, then it would become protocol across the country for young women," says Napper of Glimmer of Hope. "It wouldn't just be Pittsburgh we were impacting, we would impact young women everywhere."

Napper's dream-come-true would be to see these clinics all over the country. And while that may be in the future, right now the Clinic at Magee is making a big difference.

"We've done patient satisfaction surveys for all of our patients and the vast majority are pleased with the Clinic," says Herstine. "It saves them five or six trips to different doctors. It's a long day, but we also have a nurse coordinator who is a first contact for the patient and helps them navigate through the process. What people don't realize when they have breast cancer is that it's such an individualized disease. There's not one kind of breast cancer, and you really have to approach it from an individual perspective. Lots of different things matter. People are usually amazed at that – that it's such an individual disease. You can't just treat it the same for everyone."

Kelly Tremel was another patient of the Clinic who quickly realized the benefits that this model of care had for her whole family. As a busy 35-year old Pharmacy Technician, wife, and mother of three young boys who are involved in sports, the Clinic enabled her to manage her care with the least possible disruption to the rest of her life. "After my diagnosis, I was looking to get a plan in place and attack this cancer. I chose Magee as it was highly recommended from a breast cancer survivor that I know. I had to travel two hours to get to Magee so it was great to have all my appointments in one day. My husband and I left that day after meeting with the doctors at the Clinic feeling that we had a solid plan in place, and that we were definitely in the right place with the right people. I didn't need to take off several days, even though I was able to meet with a number of doctors and nurses."

Heather Durcho also recommends the Clinic to other young women facing a breast cancer diagnosis. "You get in. And you get out. And you have all your questions answered and can get moving on with your treatment plan. Everything was laid out in front of us for the next few months. There were less questions than if I had just met with one doctor. It's a long day but you leave there completely informed. Even though I was just starting my treatment, I still felt like I could take a sigh of relief just knowing exactly what I was facing. Instead of running here and there to see different specialists, I felt like everyone came to one location on one day, just for me."

To support research that makes a difference for young women with breast cancer, visit [www.mageewomens.org](http://www.mageewomens.org).



**A Glimmer of Hope is a Pittsburgh-based breast cancer foundation started by Diana Napper in 1994.** Diana began Glimmer of Hope to honor the wishes of her best friend, Carol Jo Weiss Friedman, who lost her battle with the disease in 1990. Diana promised that she would pursue her dream as a jewelry designer and open a jewelry business that would fund a hospice in Carol Jo's name.

As the dream evolved, Diana realized that her mission was to create a venue to support breast cancer patients and their loved ones. With that as her goal, the Glimmer of Hope Foundation was born, [www.symbolofthecure.com](http://www.symbolofthecure.com).

Through fundraising efforts such as jewelry sales and special events, Glimmer of Hope has donated more than \$3 million to breast cancer projects and has received tremendous support because of the transparency of the programs it supports, the satisfaction people receive from seeing their contributions at work, and the knowledge that the funds raised stay in Pittsburgh.

#### Here are just a few of the initiatives the Glimmer of Hope has helped to fund at Magee:

- Genetic counseling and testing for young women concerned or recently diagnosed with breast cancer
- Patient navigator to assist younger women through a myriad of choices and steps during treatment
- Breast Cancer Specialty Care Clinic
- C-View software to advance the use of 3D mammography
- Patient Resource Center and Family Lounge in the Radiation Oncology Department at Magee-Womens Hospital of UPMC
- Integrative Medicine Services:
  - Acupuncture
  - Massage therapy
- Premenopausal research projects at Magee-Womens Research Institute





# A NEW WAY TO HELP PREGNANT WOMEN WITH ADDICTION.

"This is your next door neighbor's daughter. This is your niece, your hairdresser. This is not a problem for just the marginalized. This is everyone's problem," warns Bawn Maguire, Outreach Coordinator at Magee-Womens Hospital of UPMC, and Programmatic Nurse Specialist at the Pregnancy Recovery Center (PRC).

The opioid addiction crisis in the country is crossing cultural, racial and neighborhood lines. And with more addicts fighting the disease in more places in society, it is sadly not surprising that pregnant women who are addicted would come from many different backgrounds.

Up until 2002, there was only one place in the region where pregnant women who were addicted could count on getting help for recovery. That place was St. Francis Hospital. "They had taken care of essentially all the pregnant women in Pittsburgh who had substance abuse issues," says Maguire. "They had their own OB unit, and they took care of the moms. Then, St. Francis closed. So those patients began to show up on our doorstep at Magee."

At that time, the only medication available for substance abuse was methadone. So an inpatient methadone conversion program was started at Magee. A special care nursery was opened since the babies were born with Neonatal Abstinence Syndrome [NAS] and required special care after delivery. Pregnant women with substance abuse disorder from the tri-state area came to Magee for this program. To this day, Magee remains the only hospital in this area that will do inpatient conversions for pregnant women.

## A NEW TREATMENT LEADS TO A NEW IDEA

In time, an alternative to methadone became available for patients addicted to opiates. Buprenorphine was a new option that could be delivered on an outpatient basis. Magee wanted to offer that program to the pregnant women who were coming there for help. To make it happen, Maguire and Dr. Dennis English launched the Pregnancy Recovery Center. "Dr. English was the most influential," Maguire said. "He coordinated with the Medicaid HMOs to get the funding we needed to allow the PRC to come to fruition."

Stephanie Bobby,  
Dr. Michael England,  
and Bawn Maguire,  
from the Pregnancy  
Recovery Center.





“I tell our patients that we’re going to treat them like anyone else. We’re not going to treat them specifically as an addiction patient. We want a holistic kind of care.”

-STEPHANIE BOBBY

Dr. English elaborates, “I worked with the three main insurance companies, UPMC for You, Gateway and United. We were able to establish a unique program in that the insurance companies agreed to fund the initial start-up costs of the clinic.”

Essentially, English and the insurance companies worked out a program for the women to be treated on an outpatient basis instead of an inpatient basis. “The gold standard of care in the conversion of opioid-addicted pregnant women has always been to convert them from their heroin or narcotics to methadone,” says English. “At Magee, we had always done that as an inpatient program. That means these pregnant women who were addicted were admitted to the hospital for about three days, taken off their narcotics and converted to methadone. Now we were going to be converting the women to Buprenorphine, and the conversion could be done as an outpatient.”

But the critical benefit of this outpatient model was to the pregnant women. “When women are on methadone conversion, they have to go to a community methadone clinic every morning to get their dose. Methadone is given on a daily basis,” explains English. “So there is a lot of frustration and effort for these women to have to get to a clinic every day to get their methadone.”

English also anticipated better outcomes for the mothers’ newborns. “There was evidence in the literature to suggest that babies of the moms who were treated with Buprenorphine, as opposed to methadone, would recover from their exposure more quickly and easily after they were delivered.” And in fact, that has been the case. “As we had hoped, the babies themselves after delivery do much better,” states English. “Only about a third of the babies that go through the PRC program develop NAS, which is where the babies go through physical withdrawal from drugs and have to be treated with morphine to slowly wean them off. That’s versus two thirds from our methadone group. It’s a rather marked difference. It gets the babies home quicker. Their average length of stay is about ten days, compared to fifteen or sixteen for the methadone babies.”

#### REQUIREMENTS FOR RECOVERY

The Pregnancy Recover Center also provides a structure that encourages greater success in recovery.

Dr. Michael England, current Medical Director of the PRC, talks about the Center’s unique approach. “We bring together four disciplines: the Buprenorphine-prescribing doctors, the obstetrical team, the behavioral health team and the social services team. The goal of the program is to stabilize our pregnant patients on Buprenorphine so they can manage their lives and their pregnancy. In the PRC, we offer good obstetrical and behavior health care to our patients. The importance of the behavioral health team is to help our patients understand their addiction and hopefully manage it during their pregnancy and for the rest of their lives. The PRC social services team is involved to help our patients with any additional needs or problems that they might encounter during their time with us – transportation, relationship counseling, legal issues, jobs and other things that are common in people with opiate addictions.”

Dr. English elaborates on the advantages. “We decided to use what’s called a medical home model, which tries to provide all the care that these women require at one site. They don’t have to go to a methadone clinic, and then later have to travel to other places to get their obstetrical care. It’s all done at Magee.”

According to everyone involved, the behavioral counseling component is critical. Maguire explains, “The truth of the matter is, when someone has an opiate addiction problem, the treatment for their opiate addiction is not the medication. The medication keeps them from getting sick. The real treatment for addiction is counseling. A lot of patients are resistant to weekly counseling. They say, just give me the pill and I’ll be fine. But they’re never going to get better if we just give them the pill, so we require weekly counseling.”

Weekly behavioral health counseling, prenatal care visits and commitment to Buprenorphine are non-negotiable at the PRC. Says Dr. English, “Patients have to agree to come to the clinic at the scheduled time. And we have other requirements, too. We require that they are urine-tested every time they come to the clinic to make sure they aren’t relapsing. And we require attendance at all of their clinic sessions, counseling, and obstetrical prenatal care visits. And we require them to sign a contract saying they agree to all of this. But we’re very committed to our privacy policy, so we reassure the patients that we’re not going to be giving their names to anyone. There are a lot of safeguards in place. In fact, their electronic medical records are actually hidden from other providers, which is a state requirement.”

#### THE RIGHT TREATMENT AT THE RIGHT TIME

“Pregnancy is a golden moment in these women’s lives,” English says. “Like all other moms, they want to do what’s right for their baby, so they’re willing to really work at their drug addiction and try to control it, rather than have it control them. It’s the perfect moment to try to interact with them, get them back into the health care system, and get them to understand that we’re here to treat them with dignity and respect.”

Maguire adds, “Pregnancy is a powerful motivator for women because they love their babies, and they want to have the very best outcome possible for their babies and ultimately for themselves. We want to support them because their self-esteem is extraordinarily low. They don’t feel good about themselves. Part of what we’re doing is to help women realize that they do have value and worth. So they can feel good about themselves again, and they can feel good about the fact that they’re moving forward with recovery.”

In fact, feelings of shame, distrust and low self-worth are huge barriers for pregnant and addicted women seeking help. “These ladies are coming in when they know they have a problem,” remarks English. “It’s not easy. They have social pressures. They’ve probably had run-ins with the medical health system in the past and tend to be outcasts looking in. It’s not an easy step for them to take. They’re defensive initially. So when they come into the program, we congratulate them on being pregnant and on coming into the PRC. I think initially that catches them by surprise. Our goal is to build up their self-esteem. We involve them in making decisions and improving their lives. Obviously they’re going to have to take care of their child afterward and they’re going to have to take care of themselves, so we don’t want them to be dependent on us. But we want to give them the strength, the knowledge, and the self-worth to succeed.”

“What’s most refreshing to our patients is they aren’t judged when they come in the door,” adds Maguire. “They realize we are here to support them in recovery.”

Stephanie Bobby, Patient Care Manager and Certified Addiction Nurse at the PRC elaborates, “I tell our patients that we’re going to treat them like anyone else. We’re not going to treat them specifically as an addiction patient. We want a holistic kind of care. There’s a high

level of shame and guilt coming from these patients, and it's so courageous of them to even make the phone call. Then you put pregnancy on top of that, and it's got to be terrifying to go through with this. We try to make them feel as comfortable as possible, and let them know that this is a safe haven. We're here to treat them and make sure that they're successful so they can be the best moms possible. We start with that attitude right from the beginning."

Those involved at the PRC feel that the current drug epidemic has somewhat lessened the stigma often associated with substance abusers. "In 2016, there are a lot of people who have direct contact with somebody who has a substance abuse disorder," says Bobby. "Sadly the epidemic is widely known. These days, in terms of the medical community, I get more curiosity about what we do, questions about how the clinic is run and whether the patients are successful."

Maguire adds, "We really had to work at every single level of our system to make sure that people understood that addiction is a chronic medical disease, it's not a personal failure, and that what we do in health care is work with people to bring them to the highest level of health possible."

"We never cure addiction," explains England. "Hopefully we can manage the illness by giving our patients the proper skills, insight, and motivation prior to transitioning them to a life without drugs. Addiction is not a criminal event; it's a chronic illness. With more caring people involved and more medical research being performed, there is a greater chance that we can sustain these people in remission. With our PRC program, we're treating two patients – the mom and the fetus. So if we can help the addicted patient become better, it creates the opportunity for her child to be better."

#### CHANGING LIVES

"Since 2002, conversion programs at Magee have helped approximately 3,800 women come through opiate dependence in pregnancy. That's an enormous number of women," states Maguire.

About 120 of those women came through the PRC. "Not all of them make it," says Dr. English. "For a variety of reasons, 30-40% of them will drop out of the program – whether they decide that they can't come to counseling, or they go back on street drugs, or they fail their weekly testing. We then offer those women our standard methadone conversion program. But for the majority of these women, this is the longest they've ever been sober. Most of these patients have failed multiple times on rehab programs of one sort or another. Those who remain in the program all have long periods off of drugs. They start to learn that they have some control over their addiction if they work with a group of interested and respectful providers."



Buprenorphine is dramatically changing how pregnant mothers suffering from addiction are treated.

**"Since 2002, conversion programs at Magee have helped approximately 3,800 women come through opiate dependence in pregnancy. That's an enormous number of women."**

**-BAWN MAGUIRE**

It's a unique program that's rewarding for the providers as well as the patients. "Working at the PRC is the best part of my week," states Dr. England. "Our PRC patients want care. They're defensive initially. There is distrust when they come in for their first appointment. But as they progress through their care they become less defensive and you can see part of their true personalities bloom. It is one of the reasons I love working in the PRC program. You can see this change in the patients sometimes very quickly. Once they see how they're treated by the PRC team, they drop their defenses. It's not always immediate, but it happens. From the beginning to the end of their treatment in the PRC, you see a transition that is amazing. You can see their self-esteem build as they go through the program. It's doing good for a group of people who have been often overlooked by society."

Stephanie Bobby couldn't agree more. "Even on day two, most of our women will look and feel completely different. You can see it. It's so nice to get to know the real person while they're in recovery and see their personality blossom when it has a chance. At the PRC, I get to

work with these women for their entire pregnancy. For me, it's very rewarding to see from point A to point B – from the time I first meet them when they're feeling awful, to delivery when they're proud moms. I feel good sending the patients out to community providers, because we've made as much of a difference as we possibly could in that time during pregnancy."

#### CHANGING HEALTH CARE

Today, there are five doctors at Magee who have received the extra training and a special license necessary to write prescriptions for Buprenorphine. All of them are OB/GYNs, rather than psychiatrists – another unique aspect of the PRC's conversion program.

Of course, research opportunities are also an advantage the center offers. "Pregnant women respond to and metabolize drugs differently than non-pregnant women or men," remarks English. "And not much research has been done on how pregnant women metabolize Buprenorphine. Researchers at Magee received approval from some of our patients to have them participate in a study looking at the dosing of Buprenorphine and how much it takes to appropriately dose a pregnant woman compared to a non-pregnant woman. It appears that these women will require much higher doses of Buprenorphine to control their symptoms and get the appropriate blood levels as compared to non-pregnant women. Once the study is published, it will be a very important addition to the literature on the treatment of addicted pregnant women and what the appropriate dosing of Buprenorphine is for those women. It's exciting stuff and it could only have happened at a place like Magee."

The PRC is also working on studies in conjunction with behavioral counselors at Western Psychiatric Institute and Clinic of UPMC. "We're trying to develop longitudinal studies about what happens to these moms after they go out of the program," English says. "What social services are particularly advantageous for us to provide to try to improve their success rate? The fact that this is being done at an academic center will hopefully lead to some publications in literature on the advancement of care of these patients."

Bobby describes yet another research project at the PRC: "We have a navigator research program going on right now, and the women who qualify in our clinic are actually working one-on-one with a patient navigator. So, for example, if they need assistance at the welfare office, the navigator would go with them to the welfare office. If they needed assistance finding the counseling building, they would go with them and help coordinate all of that care."

Now that the program has proven to be successful, the PRC plans to grow. "We're hoping to initiate this with other providers and institutions to try to expand the clinic," says English. "We purposely started this relatively slowly to make sure that we knew how to manage the unique needs of these moms, and we were more certain about what the outcomes were going to be. Now it's time to expand. I know Dr. England and some of our staff are working at trying to bring this to other sites. We've also had interest from a number of other health care systems and hospitals across the country that have come to visit us to talk about how to adopt similar programs."

It's definitely a labor of love for all involved. "Everyone who's in the program wants to be in the program," remarks England. "We live on a minimal budget with the PRC. The physicians are in the PRC because we want to be in the PRC. We are not just going through the motions. We enjoy it, and I think the patients know that. The PRC patients are a group of people that I never thought that I would want to work with for an extended period of time, but I have found joy in treating them and seeing them enjoy being treated fairly and with compassion. In patients with chronic illnesses, you often don't see quick changes. In the PRC, we see change very quickly in some of these patients. They go from patients that can barely stay awake on their first admission to personalities that you or I would be proud to have. Unfortunately, they were just in the wrong environment at the wrong time and got addicted."

Bobby adds, "Our goal is to get these women in recovery and give them the independence, confidence and strength to remain in recovery, and be wonderful moms to their new babies."

**To support research that makes a difference for pregnant women, visit [www.mageewomens.org](http://www.mageewomens.org).**

**For one patient's story of recovery through the PRC, see story on the following page.**





## ONE RECOVERY STORY WITH TWO VERY HAPPY ENDINGS.

One of Lindsay Duggan's counselors gave her a present with the following inscription on it: "The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss and have found their way out of the depths..."

The depths that Duggan has seen began when she went away to college.

"In college, the cool kids were drinking. The cooler kids smoked weed. And the coolest were snorting things," Duggan remembers. "And I had never seen anything like it. I was raised in an upper class home and was so naive. I didn't have the perfect home life. My father was an alcoholic who my family had to get away from. But in high school, I was on student council. I was involved with Students Against Drunk Driving. I was our class vice-president. I was one of those super involved kids and actually more of a prep. I even graduated towards the top of my class. But when I went to college, I made the mistake of trying these things and that's how it started."

Duggan eventually left college because she was afraid of how often she was snorting crushed up pain pills. It was then that she first realized that she was addicted.

"For the first time in my life, I felt myself going through withdrawal," she said. And without easy access to pain pills, she found friends from high school who were using heroin. "After only using heroin three times, I knew I was addicted to it. That's all it took. And I began using it every single day, multiple times a day. And I did this for years."

The new heroin habit was only the beginning of her struggles. Her boyfriend at the time was also an addict, and Duggan became pregnant. Then she found out she was pregnant with twins.

"When I first realized I was pregnant, it was horrifying and lonely. I realized I was opiate dependent. But I didn't want to tell anybody, and there was so much going through my head," she said. "The people who knew I was on opiates didn't know I was pregnant. And the people who knew I was

Lindsay Duggan (right)  
with her mother Mary Ann,  
and daughters Isabella  
and Gabriella.



**“Sometimes when you’re in treatment, you know what people are thinking. But everyone at the PRC truly cared and made me feel like I really had a chance.”**

**-Lindsay Duggan**

pregnant, like my OB, didn’t know about my drug use. I was afraid of who they would call or report me to.”

This fear and confusion led Duggan to the Internet, which frightened her even more.

“I read things about detoxing yourself. And then I read about how detoxing while pregnant can cause a miscarriage. And I also read about the danger of being in withdrawal when pregnant. Basically, I read too much on my own. I was afraid to stop. I was afraid to keep going. I felt utterly helpless and hopeless.”

She was living at various run down places with her boyfriend. But she didn’t want to come home for fear of what her mother, Mary Ann, would do or think.

Duggan did eventually tell her mother, who knew about her addiction, that she was also pregnant with twins. But by now, she was living and sleeping in a car. She knew she needed rehab, but Duggan didn’t think there was any place that could help her with both her addiction and complex pregnancy.

After a few months of living like this, her mother tracked her down to plead with her to leave to get help, and get away from her boyfriend.

“He controlled me so much that I was certain that leaving him would be bad,” Duggan said. “He was the one who knew a dealer for Suboxone, which I was buying on the streets to stay out of withdrawal and avoid using heroin. But I refused to leave until I knew there was a rehab that would take me.”

Fortunately, her mother convinced her they could find help. So they packed up the car and drove to her sister’s house in Houston, Texas. Her sister told Duggan about a big rehabilitation facility there that treated pregnant women and, just as importantly, had open beds.

“Finding a bed in a rehab is very hard,” she said. “Even if an addict makes the decision to try to get clean, there isn’t always a place that will take them. You have a 6-12 hour window of opportunity to get treatment for an addict. After that, they’ll be so sick that they have to start using again. So when people have to wait days to get in a rehab center, it doesn’t work.”

But when she got to Houston, the facility wouldn’t take her because of the twins.



“They thought I was too big of a liability,” she remembers.

Desperate for help, Duggan and her mother drove to several other centers in different states on their way back to Pittsburgh, calling the facilities on the way.

“I even went through the screening process at a few places and thought I was in. But for one reason or another, I was turned away. Whether it was because I was having twins, or because I was from out of state, or because they didn’t have a bed...I just couldn’t find the help I needed. And I was going through withdrawal during this two-week trip. It was truly awful,” she said.

But Duggan got a ray of hope when she made a call to Pennsylvania from the road.

“We were more than halfway home after being turned away by the 5th or 6th place. And I called Jade Wellness Center in Monroeville and told them about the twins. I had gone there for treatment when I tried to quit once before.”

The counselors at Jade had just heard about Magee-Womens Hospital of UPMC opening a new Pregnancy Recovery Center (PRC). Duggan made it to the PRC within a few days of returning home.

And Duggan’s first impression when arriving at the PRC?

“Immediate relief,” she said. “As soon as I talked to Stephanie Bobby at the PRC, I felt like the weight of the world was immediately off of my shoulders. For the first time since I found out I was pregnant, I thought maybe this might turn out OK. Maybe I won’t go to jail. Maybe I won’t lose my babies. Maybe they won’t be born addicted. Maybe I won’t lose my whole family. And I was glad it wasn’t an inpatient program. Because any pregnant addict, unless they want their babies to end up in foster care, needs to learn how to function in society. They need to learn and get a lot of counseling and support to get clean. And committing long-term to a program is important.”

Duggan feels that one of the keys to her successful recovery was that she was finally at a place where the care and treatment was complete and transparent.

“I was now getting completely honest and open medical care. Nothing was a secret. Just being able to tell someone everything was a huge relief,” she said.

She felt she was also getting care without judgment.

“Everyone at Magee was just incredible,” Duggan said. “They were so open-minded and kind and generous and respectful. I could go on and on! They only wanted to help me. Sometimes when you’re in treatment, you know what people are thinking. But everyone at the PRC truly cared and made me feel like I really had a chance.”





And although the PRC has some strict rules, Duggan didn't feel it was hard to comply.

"It was tough love, but certainly not too tough. The rules were very fair. It's understandable. You're dealing with addicts. If you can't work the program, it's not going to help you. It wasn't too strict at all. Having to check in once a week with a counseling group is nothing. It actually felt doable and it was perfect for being pregnant with my energy being down and needing to go to my other appointments."

Duggan also took comfort in knowing that her medication was consistently available and medically monitored. But for her, the medication was actually secondary to the people.

"Even if they didn't offer the medication, the PRC was amazing. Just knowing there are people at Magee who care and can help. It wasn't just the physical dependence and the medication. It was the emotional and mental support they gave me from the moment I walked in," she said.

Plus, the doctors and nurses at the PRC were there for her when it was time to deliver her babies, as well.

"When I was induced, the PRC physicians were in touch with the doctors who delivered the babies to help with my pain meds. I was off of them the day after I delivered. After everything I had been through, it was an amazing birth and everything was perfect. And my daughters, Isabella and Gabriella, were born free of addiction. Everybody we met at Magee helped us. And I'm so grateful."

"I couldn't have done this without my mother and without the PRC," Duggan continued. "I feel really bad for what I put my family through. But that's active addiction. Stealing, lying, cheating. Nothing matters when you're in active addiction. That's why getting moms the help they need is so important. Otherwise they don't stand a chance, and neither do the kids."

Duggan wants to share her story now, hoping that others can avoid her mistakes. Or if they do make mistakes, at least find a place like the PRC to get help.

"We desperately need facilities like the PRC," she says. "And not just in Pittsburgh. We need them all over the country. I drove across half the country trying to find help and they opened right here practically in my backyard just in time to save my family. There isn't another center in the nation that does what the PRC does. Trust me...I drove around for two weeks looking for it! Magee was a godsend."

Duggan is also aware of the stereotype of those addicted to opioids, because she was also surprised by the people she's seen at treatment and recovery centers.

"You expect certain people that look a certain way, and you get there and it's normal looking people. Not just the typical image you have of a drug addict. Most addicts aren't poor. They are professionals. They are teachers, bus drivers, policemen, businessmen. They are people who had an accident and got addicted to something like Vicodin for the pain ever since. It's not the stereotype. It's often people with money to be able to buy the drugs."

And she warns that the problem needs to be addressed before it gets even worse.

"I lived that life and it's all about heroin and prescription drugs. And it's taking over our neighborhoods. And these are nice neighborhoods. All the women I met in rehab are nice, professional ladies. This isn't just a poor person's addiction."

Looking back, she doesn't think she would have gotten clean without the motivation of taking care of her kids. And just as she got over her addiction to save her children, she feels like their arrival saved her life.

"I think it was God's plan to get me clean. I wouldn't be where I am right now without my girls. I don't have a second to do anything else but take care of my kids, to be honest. And active addiction takes time and a lot of work. No one matters but yourself when you're an addict. I couldn't be an active addict with one kid, let alone two. All my time and effort is now for them."

Duggan is proud to be one of those people who have found their way out of the depths, now with a new purpose and direction.

"I'm lucky Magee started the program when they did. I know I'm lucky I'm alive. And I'm even luckier I have these girls to live for."

**To learn more about the Pregnancy Recovery Center's history, mission, and people, see story on page 10.**







# RESEARCH DISCOVERY:

## Breast Cancer Survivors Make Excellent Advocates for Clinical Trials.



Dr. Carola Neumann

How can we improve breast cancer research and outcomes? How can we play a critical role in both making patients aware of their choices with respect to participation in clinical trials and in ensuring that the studies are designed in such a way that they are maximally relevant and patient-focused to the population that the studies are designed to serve? Those are some of the goals of the Breast Cancer Research Advocacy Network (bcRAN). Here at Magee, bcRAN is building a partnership between breast cancer survivors, trained as advocates, and scientists, to accelerate the progress of cancer research and advocate for clinical trials.

We talked to bcRAN's co-leader, Dr. Carola Neumann, Associate Professor in the Department of Pharmacology at the University of Pittsburgh, and Program Director of the bcRAN program "Advocating for Clinical Breast Cancer Trials in Allegheny County". We also talked to bcRAN's Program Manager and advocate, Karen DiVito, a breast cancer survivor.

### Tell us how the bcRAN came to be.

**DR. CAROLA NEUMANN:** A couple of years ago, it became evident to the research community that survivors must play a bigger role in research because they have so much to contribute in terms of the validity, design, and focus of the studies. That is when a core group including Dr. Nancy Davidson (Director of the University of Pittsburgh Cancer Institute and Director of the UPMC Cancer Center), Dr. Adrian Lee (Director, Women's Cancer Research Center at Magee-Womens Research Institute) and Dr. Steffi Oesterreich (Director of Education at the Women's Cancer Research Center) proposed creating a breast cancer research advocacy group here. They approached me and Dr. Priscilla McAuliffe, who is a breast surgeon at UPMC, to realize this goal.



With a small group of survivors, who were already engaged in the Pittsburgh breast cancer community, we began to build a network of advocates. Initially, through monthly meetings, and inviting participation of researchers, breast cancer clinicians and other professionals, we created an environment of collaboration and endless opportunities for bcRAN to have an impact. It is imperative to have everyone's perspective in order for our goals to be achieved.

Karen was active at Magee in the peer-to-peer program where newly diagnosed patients are matched with survivors. At bcRAN, her role is as a survivor/advocate and I'm the researcher. It's important to have everybody's perspective.

### **Karen, how long have you been involved with bcRAN?**

**DIVITO:** I've been involved with the peer-to-peer support program at Magee for about eight years. Because of my regular inquiries about research updates, my oncologist, Dr. Shannon Puhalla, recommended that I speak with Carola to learn more about the advocate role. It was a natural transition and I started working with bcRAN about two years ago. We have twelve advocates in the program currently, each bringing something different to the group, based on their experiences.

### **Why do survivors make such good advocates for clinical trials?**

**NEUMANN:** Researchers and survivors come from different perspectives: survivors bring a non-scientific viewpoint to the research process. Because many of our advocates have knowledge of others' disease experiences, this creates a powerful, collective patient perspective far beyond the individual experience. The research and, ultimately, the patient benefit from this comprehensive strategy.

**DIVITO:** A survivor research advocate can be a resource to educate new patients. A survivor is particularly sensitive to a patient's needs and concerns and can empathize with the overwhelming amount of information that is being delivered. For example, at the appointment when first learning of their diagnosis, most patients shift into survival mode. Clinical trial information is probably not a priority question.

**NEUMANN:** The rates of clinical trial participation are still too low for breast cancer trials. Nationwide, the participation in breast cancer clinical trials is about 12%. This low participation rate makes it more challenging for principal investigators to make the trials significant enough to change the standard of care.

**DIVITO:** Advocates can have peer-to-peer conversations at a later time (after the initial diagnosis), when it is better for the patient to hear more about clinical trials and to decide if that is a good option for them.

### **Does bcRAN allow researchers to do what they do better?**

**NEUMANN and DIVITO:** Yes!!!

**DIVITO:** All of us who are advocates support research, and a big part of research is clinical trials. There are obstacles and barriers that sometimes prevent clinical trials from being as efficient as they could be. Part of our mission is to learn about the reasons why breast cancer patients choose not to join clinical trials. What barriers are they experiencing? How can we make sure that patients learn about all the options they have? Is there misinformation out there? Are there transportation barriers? Survivors tend to connect with other survivors. So I can give my voice, along with the input and the knowledge that I've collected from every breast cancer patient that I've talked with over the years. That feedback is essential and can be incorporated into the design of future studies so that they're more patient-centered. These improved study designs are then more likely to appeal to a woman who's presented with a clinical trial option.

**NEUMANN:** Receiving feedback from breast cancer patients is truly essential. When researchers review grants in study sessions, the inclusion of survivors in the review process is a very powerful experience. Research advocates bring a different perspective based on their priorities. For example, in a recent grant review, a study was discussed defining a chemotherapeutic drug that has been around for over 20 years. While the researchers were focusing on the feasibility of the proposal, one of the advocates commented, "This drug is 20 years old and has terrible side effects. We need to fund studies exploring newer and better treatment." That is what we need. That is an example of where survivors share their experience and priorities and say, "I have taken this and I want something better."



**DIVITO:** Advocates can educate and listen to patients' fears or questions. We don't actually recruit participants for specific trials, but we do encourage patients to make inquiries and consider participation, explaining the potential health benefits for both future patients, and perhaps, for the individual. We couldn't have achieved better survival outcomes without new treatments that were validated through clinical trials.

**NEUMANN:** Let us give you an example. 30 years ago there was no efficient treatment for breast cancer patients diagnosed with a HER2-positive cancer. Back then, in the 1980s, there was little understanding of genetic mutations and their role in driving cancer, no map of the human genome, and no targeted medicines for people with breast cancer. Today we have HER2-targeted medicines like Herceptin that have clearly improved the lives of people with breast cancer and their families, as well as future drug development. This was only possible through the participation of thousands of patients in clinical trials. In a way it is really simple, without any clinical trials we will not see new breakthroughs in breast cancer treatments. Some of the obstacles that make patients decide not to join a clinical trial are related to a lack of information.

**DIVITO:** We often hear that patients say they don't want to be a guinea pig or receive a regimen that is unproven. It is a common belief. But current treatment is never withheld, and patients receive the standard treatment in addition to a new clinical drug. Patients are in control during a clinical trial and can opt out of clinical trials at anytime.

**NEUMANN:** Another fear we have encountered among patients deciding against clinical trial participation is the assumption that they may end up in a "placebo" group where they won't be given any treatment. That is not true. As Karen said before, standard of care is never withheld in a clinical trial. Participants usually receive either the treatment to be tested plus standard care or standard care alone.

### **Tell me about boot camps.**

**NEUMANN:** The bcRAN boot camp is an educational day for research advocates. We want our advocates to be involved in research and that requires some basic knowledge about breast cancer research, current treatments, how the diagnosis is made, breast anatomy and surgery, and survivorship. We have usually 4-5 clinicians speaking about these topics. Another important part of the day is the keynote speaker. The past year we had an advocate from the National Breast Cancer Coalition (NBCC), Carol Matyka. She spoke about research advocacy and the importance of clinical trials. Her presentation was very well received.

**DIVITO:** The advocate's goal is not to become a "scientist", but to be an educated, informed survivor/advocate. The learning process

is bi-directional. While researchers can educate us about new trials, we can be a voice informing researchers about making trials more patient-centric, and reminding them of the importance of more immediate treatments.

### **Are there other breast cancer research advocacy groups that you work with?**

**NEUMANN:** While other patient advocacy groups exist, ours is unique because of our network model. Our advocates provide information to the researchers, but are also a link back to the community.

**DIVITO:** National breast cancer advocacy groups do exist and provide opportunities for us to receive training and network with our peers. Advocates can have a political focus, a fundraising focus, and/or a research focus. Ours is focused on research.

### **Did you encounter any initial resistance from researchers to getting input from advocates regarding clinical trials?**

**DIVITO:** I felt the opposite. We have Principal Investigators, PIs, who are waiting to present at our advocate meetings. They are anxious to inform us about what they are studying because they, too, are passionate about this mission. We've been invited for the past two years to the Researcher's Retreat, and that's coveted time. To get all of the researchers away from their labs for two days and then to share that agenda and allow us to have a role, that's an incredible honor.

**NEUMANN:** Dr. Steffi Oesterreich is organizing a meeting at UPCI for Invasive Lobular Breast Cancer (ILC) this year on September 29th and 30th. An advocate from our group, Heather Hillier is co-chairing this meeting. Involving advocates in such a role is a great way to create the collective perspective of survivors and researchers. About 150 people will participate including 24 international leading scientists in ILC and local advocates who will be part of one of the sessions. This meeting is the first of its kind on ILC, a breast cancer that is difficult to detect by mammography.

### **Breast cancer gets a lot of publicity. Do you think people are starting to be less motivated by the message?**

**NEUMANN:** Prevention, awareness, and diagnosis have been successfully promoted for the past decade. More breast cancers are detected earlier which clearly has improved prognosis. But, it is equally necessary to send a message addressing metastasis. More and more patients live a productive life with metastasis. However, in a culture focused on survivorship, those with metastatic breast cancer who will be in treatment for the rest of their lives can feel isolated and misunderstood. Our treatments have clearly come a long way to live a life beyond breast cancer. Many patients participating in clinical trials have made this possible, but we clearly need more patients to participate in clinical studies.

**DIVITO:** As a peer-to-peer support survivor, I can say that 9 out of every 10 women that I talk to had none of the known risk factors. There wasn't a family history. Other co-morbidities, such as excess weight, were not factors, and these women felt that they were living healthy lifestyles. So while it's important to tell everyone what we have learned about breast cancer prevention at this point, it is not enough. Additional risk factors need to be identified along with better treatment options.



### What would you like to see moving forward?

**DIVITO:** In terms of a long-term hope, I would like to see this program duplicated for other types of cancers. The local chapter of the National Ovarian Cancer Coalition has reached out to us and attended some of our meetings. They had a representative at our boot camp and are observing our model to see if it can be translated to the ovarian cancer community. In the meantime, we continue to educate patients about clinical trials, to collaborate with researchers at all phases of their studies and to reach out to survivors who would like a role as advocates.

We would like to expand our group for a variety of reasons. We want our group to stay diverse so that it is an accurate representation of the breast cancer community. As you know, there are a lot of different sub-types of breast cancer. There are different stages of breast cancer. There are different issues depending upon your age when you're diagnosed. So far, we've done a fairly nice job of incorporating diversity into our advocates. We now have a gentleman who is a bcRAN advocate and he is bringing his perspective to the model, making it even more comprehensive.

**NEUMANN:** Our biggest goal is to support breast cancer patients with information about all the options they have. That also includes the option to participate in clinical trials. We won't have new benefiting changes in standard of care without clinical trials. Therefore, we want to grow the network (bcRAN) and expand our outreach work. We have been very fortunate in the past to recruit bcRAN members who are all genuinely interested in volunteering for this cause by going beyond their own experiences. In addition, our efforts were recognized by Komen Pittsburgh, which has funded bcRAN now for the second year in a row to promote clinical trial awareness in Allegheny County. Our efforts include raising public awareness, offering education, and investing in community outreach. Truly, it has been an extremely fulfilling and rewarding experience for me.

To support breast cancer research, visit [www.mageewomens.org](http://www.mageewomens.org).

To learn more about bcRAN, visit [upci.upmc.edu/wcrc/patientAdvocacy.cfm](http://upci.upmc.edu/wcrc/patientAdvocacy.cfm).

To learn more about clinical trials, visit [upci.upmc.edu/clinical\\_research/trials.cfm](http://upci.upmc.edu/clinical_research/trials.cfm).

## PATIENTS GET A BETTER VIEW WHEN FACING CHEMOTHERAPY.



Patients at Magee-Womens Cancer Center often have a long wait while receiving treatments, sometimes sitting for up to eight hours in a chair. But thanks to the generosity of Hotel Monaco Pittsburgh, and the creativity of design and production firm Endagraph / Dreamakür, the view has improved dramatically.

As part of their "Random Acts of Kimpton Kindness" campaign, Hotel Monaco Pittsburgh saw the work of Dreamakür and realized it was a great way to help patients undergoing cancer care. Dreamakür specializes in creating rooms that serve as "distraction therapy" for patients facing long treatment plans in hospitals or other facilities. Their colorful and engaging room designs help the time pass more pleasantly, and can have a real impact on a patient's morale.



"We were excited to have been asked to be a part of this project and the opportunity to transform an area of the Cancer Center at Magee utilizing our Distraction Therapy wall images," said Jim Nash, President of Dreamakür. "Our goal is to design and create imagery that changes the environment and allows the viewer to imagine being someplace other than a hospital room. We hide messages of hope and encouragement, along with cute little forest animals within the image just to surprise and create a smile. Smiles are healing and we believe we can help make a difference with the patients' hospital experience."

Linda Ankrom MSN, MHA, RN, Unit Director of Magee-Womens Cancer Center, says that the wall has made a big difference to patients.



"We as clinicians are charged with caring for the mind and the body," Ankrom said. "This room helps us meet our goal of taking care of our patients. We are very grateful for this gift and the talents of everyone involved. Hotel Monaco and Dreamakür have demonstrated their commitment to making our community a better place. And we cannot thank everyone enough for making this room a reality."



## Pittsburgh Penguins Alumni Association Establishes Memorial Research Fund

"The first time I met Steffi and Adrian, I knew we wanted to support their work," said Heather Hillier of Drs. Oesterreich and Lee, both researchers at Magee-Womens Research Institute and the Women's Cancer Research Center.

As a breast cancer survivor, Heather—wife of former Pittsburgh Penguins player, Randy Hillier—has developed a passionate drive to support cancer research. To help accomplish her goals, Heather has enlisted the help of Mario Lemieux, Jay Caufield, Kim Clackson, Dave Hannan, Pierre Larouche, Bryan Trottier and the entire Pittsburgh Penguins Alumni Association.

With almost \$300,000 raised from private donations and community fundraising events such as Skate with the Greats and their annual golf outing, the Pens Alumni Association announced the establishment of the Nicole Meloche Memorial Breast Cancer Research Fund at Magee.



Left to right: Adam Brufsky, MD, PhD, Shannon Puhalla, MD, Jay Caufield, Alicia Caufield, Randy Hillier, Heather Hillier, Gilles Meloche, Sophie Meloche, Natalie Lemieux, Lauren Lemieux, Mario Lemieux, Steffi Oesterreich, PhD, Adrian Lee, PhD

Nicole was 39 years old when she was diagnosed with inflammatory breast cancer in 1990. At the time, she and her husband, Gilles Meloche, former Pittsburgh Penguins player, coach and then amateur scout for the Pens, lived in Montreal with their two young children, Eric and Annie. Nicole bravely fought her breast cancer and amazed her doctors when she went into remission. Nicole was a champion.

To those around her, she was the model of courage, perseverance and determination. Unfortunately, the cancer metastasized and on November 18, 1993, she lost her gallant fight.

"Nicole holds a special place in the hearts of the Penguins alumni members and through their efforts, they have decided to fund a research project at Magee-Womens Research Institute that will help us better understand the why and how of metastatic breast cancer," explains Hillier.

When asked about naming this special fund after Nicole, Gilles replied, "It's really touching that so many years later, I am still in contact with alumni. I am touched that they, along with Heather, wanted to create this fund in honor of Nicole. I know the research will help so many families – and they will not have to go through what we did."

In her remarks at the event to announce the establishment of the Nicole Meloche Memorial Breast Cancer Fund, Dr. Oesterreich shared that the research performed at Magee with these funds will be specifically targeted at improving the outcomes in women with metastatic breast cancer. "We are hoping to achieve some exciting and significant steps forward in fighting this dreadful disease," she said.

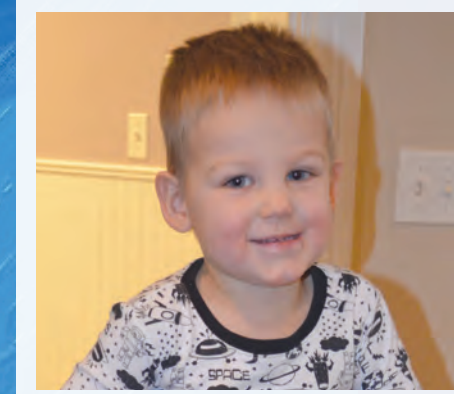
To learn more about how you can support this effort, please visit [mageewomens.org](http://mageewomens.org) or the Pittsburgh Penguins Foundation at [pittsburghpenguinsfoundation.org/about-us/pens-alumni](http://pittsburghpenguinsfoundation.org/about-us/pens-alumni).



### Key Facts About Metastatic Breast Cancer:

- Metastatic breast cancer claims over 40,000 lives every year.
- While 30% of all breast cancer patients will metastasize, only 2% of all research funding goes to metastatic breast cancer research.
- 100% of breast cancer deaths occur because of metastasis, and almost 100% of people whose breast cancer has metastasized will die from it in the United States alone.
- Many metastasis researchers believe that metastatic breast cancer could become a chronic, rather than terminal, disease, therefore funds are needed to do research to develop effective treatments.

## FINDING A CAUSE AND SHARING THEIR PASSION AND SUPPORT



Lauren Garraux's pregnancy was uneventful for 36 weeks and three days. Then unexpectedly, her water broke, and baby Rex entered the world early. At first, all appeared fine. His Apgar score was good. But within a few minutes of life, Rex started having difficulty breathing. After an evaluation, it was determined that Rex's lungs weren't fully developed, and he had an infection. He was admitted to the Neonatal Intensive Care Unit (NICU) at Magee-Womens Hospital of UPMC.

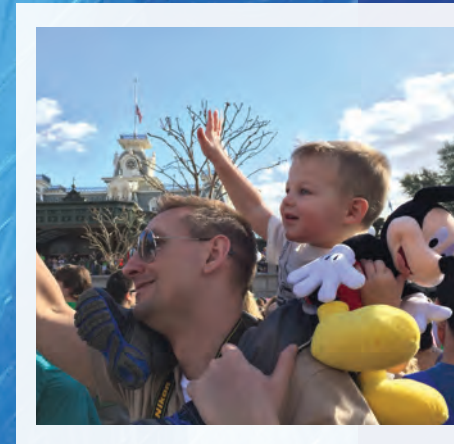
Dave and Lauren Garraux had chosen to have their baby at Magee specifically, knowing that a high level of care was available through the NICU. Some of their friends had chosen facilities based on the appearance of the birthing suites, proximity to their homes, etc. The Garraux's weren't thinking they would have a need for NICU services, but they were comforted that they were there. As it turned out, the NICU was vital in allowing Dave and Lauren to take their "little buddy" home.



Although Rex only had to stay one week, the Garraux family wanted to stay involved and give back after experiencing firsthand the courage and commitment of the doctors, nurses, and staff. They had been searching for a cause to support about which they felt passionate and, after their experience with and in the NICU, they had certainly found one.

Dave and Lauren's first step was becoming involved with the Parents Advisory Committee and attending monthly NICU socials, during which Advisory Committee members and their children ("NICU graduates") share their experiences with parents and families with children currently in the NICU.

The Garraux's also became one of the sponsors of the annual NICU Reunion at the Pittsburgh Zoo, and together with Dave's parents and law firm, one of the sponsors of Savor Pittsburgh, an event with proceeds benefiting prematurity programs at Magee.



In 2015, Dave and Lauren wanted to do something tangible for the families who need the care of the NICU. They made a donation to refresh a NICU nesting room, making it more welcoming and comfortable. Nesting rooms are like a hotel room where parents who are preparing to go home can stay a night or two with their baby and be close to nurses in case there is a need. With over 2,000 babies per year needing the care of the NICU, the nesting rooms are used frequently.

Dave and Lauren had one request. With a name like Rex and as a tribute to him, they asked for a dinosaur presence as part of the renovated room. A picture of the Carnegie Museum of Natural History's Dippy the Dinosaur will be incorporated into the area. The Garraux's can't wait to see it!

Rex, now 2, has a little brother, Max, who is 4 months old. While Max waited until his due date to be born, Lauren fell down the stairs during her pregnancy and went through a scary time in the emergency room at Magee. Again choosing Magee because of the care, both pregnancies deepened Dave and Lauren's commitment to reach out to people with similar experiences and ask them to get involved as well.

On a recent trip to Walt Disney World, Dave watched Rex running and playing. He was amazed at where Rex is now versus his start in life. Both Dave and Lauren are so thankful and grateful to have the opportunity to give back. He and Lauren have determined that their next step philanthropically is to make a multi-year commitment to another project within the NICU that needs their help. They will be scheduling that meeting soon.





## Honoring Caregivers and Expressing Gratitude

When Barbara Hall was diagnosed with breast cancer in 2015, both her mother and her neighbor recommended Magee based on the care they had received here. Barbara made the decision to travel to Magee as well, even though it was almost a two-hour trip from Hollidaysburg, Pa.

With help from her husband, daughter, and neighbor, Barbara received treatment at Magee, including several months of chemotherapy. Those months were long and difficult, and she felt like she had landed on another planet. Barbara was overwhelmed, afraid, and unsure of what to expect week by week.

Jen Matthews, her nurse in the Women's Cancer Center at Magee, was a steady guide, in addition to a medical professional. She helped ground Barbara in her new reality, and made the "new planet" less intimidating. Jen brought comfort to Barbara and her husband, Thomas, at a time when it was really hard to find stability and solace.

Once chemo ended, Barbara and Thomas were so thankful for Jen's constant care and support; they decided to make a gift in her honor. Jen was a true gem and a steady and welcome presence during some very long and difficult months.

The Hall's also agreed to share their story in Magee's annual National Doctors Day (March 30) and National Nurses Day (May 6) donor mailing. Participants were asked to send messages of gratitude to their doctors, nurses, teams, and departments with contributions in honor of the caregivers.

According to Barbara, coming to Magee was "more than worth the trip." She feels blessed to have been treated at a renowned university teaching hospital and pleased to have found appropriate ways of expressing her appreciation.

## PRIME 1 BUILDERS HELPING IN THE FIGHT TO END PREMATURE BIRTHS

Mary Anne Meade was 40 when she met the love of her life. First marriages for both, Mary Anne and Dan Meade used in vitro fertilization to conceive triplets. Through several complications, Mary Anne lost two of the fetuses. Being a physician assistant, she knew when looking at the ultrasound screen that there was only one fetus remaining.

With Mary Anne's high-risk pregnancy, the Meade's were referred to Dr. Hyagriv Simhan. They were told he was the best in the city. What they found was not only an exceptional doctor, but also a compassionate man. Dr. Simhan is Chief of the Division of Maternal-Fetal Medicine and Medical Director of Obstetrical Services at Magee-Womens Hospital of UPMC.

Because Mary Anne had suffered a perforated uterus—and a perforated bladder—uterine rupture was possible. Dr. Simhan determined that she needed a mandatory C-section. Mary Anne delivered a beautiful baby girl, Maura, who is now 8 years old.

For Mary Anne's second pregnancy, Dr. Simhan welcomed the Meade's back, as another C-section would be required. Dr. Simhan got to know Mary Anne and Dan even better, and they developed a friendship that continues today. After a successful pregnancy, the Meade family welcomed son Connor, who is now 6.

As a way to say thanks, Dan and Mary Anne have sponsored Savor Pittsburgh (an event with proceeds benefiting prematurity programs at Magee) for four consecutive years through their company, Prime 1 Builders, Inc. Prime 1 is a sought-after builder of custom homes, distinctive renovations, and commercial workspace construction.

Prime 1's involvement in Savor Pittsburgh started small by sponsoring a basket for the event. The company's participation has grown, and Prime 1 was a \$5,000 Crystal Cup Sponsor in 2015. Dan and Mary Anne also gathered a big group of friends, purchased VIP tickets, and enjoyed a fun night!

While Mary Anne and Dan were fortunate not to need Neonatal Intensive Care Unit expertise when their two children were born, they've had friends who have gone through that heart-wrenching experience.

"It's amazing to see these tiny babies and recognize that 10 years ago, they would not have lived," Mary Anne said. "Families have children that survived because of the research that has taken place at Magee-Womens Research Institute. But research takes lots of money, which is why Prime 1 Builders, Dan, and I are involved."







Carl Hubel, PhD



Robert Powers, PhD



Janet Catov, PhD

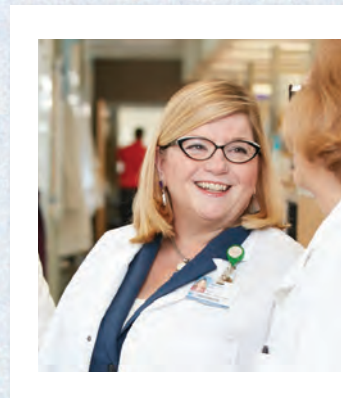


Jim Roberts, MD

**Carl Hubel, PhD; Robert Powers, PhD; Janet Catov, PhD; and Jim Roberts, MD**, received a four-year, \$3.7 million grant from the American Heart Association (Go Red For Women initiative) entitled: "Womens Cardiovascular Health and Microvascular Mechanisms: Novel Insights from Pregnancy". They will examine whether certain pregnancy-related blood vessel changes can uncover mechanisms of later-life cardiovascular disease (CVD) in women, identify women at highest risk and guide new interventions to help them.

The causes of heart disease, which damages the inner walls of the blood vessels and can lead to spasms and decrease blood flow to the heart muscle, known as microvascular dysfunction, are unclear, said principal investigator, Carl Hubel, Ph.D., associate professor of obstetrics, gynecology and reproductive sciences at the University of Pittsburgh School of Medicine and MWRI investigator. During pregnancy, profound metabolic and cardiovascular changes occur, putting extra stress on a woman's body and requiring the heart and blood vessels to work harder. Researchers believe that studying these cardiovascular changes may reveal early mechanisms of CVD.

"This grant is an important next step for our research team in the ongoing assessment of using pregnancy as a lens to understand CVD in women throughout the life span," explained Dr. Hubel. "Microvascular dysfunction is a devastating public health challenge because almost two-thirds of women who die suddenly of coronary heart disease have had no previous symptoms. We hope to build on the research of our previous studies by identifying mechanisms of CVD in women that are unmasked or perhaps even caused by pregnancy. By examining these relationships, we aim to discover early heart disease risks in women as well as the causes."



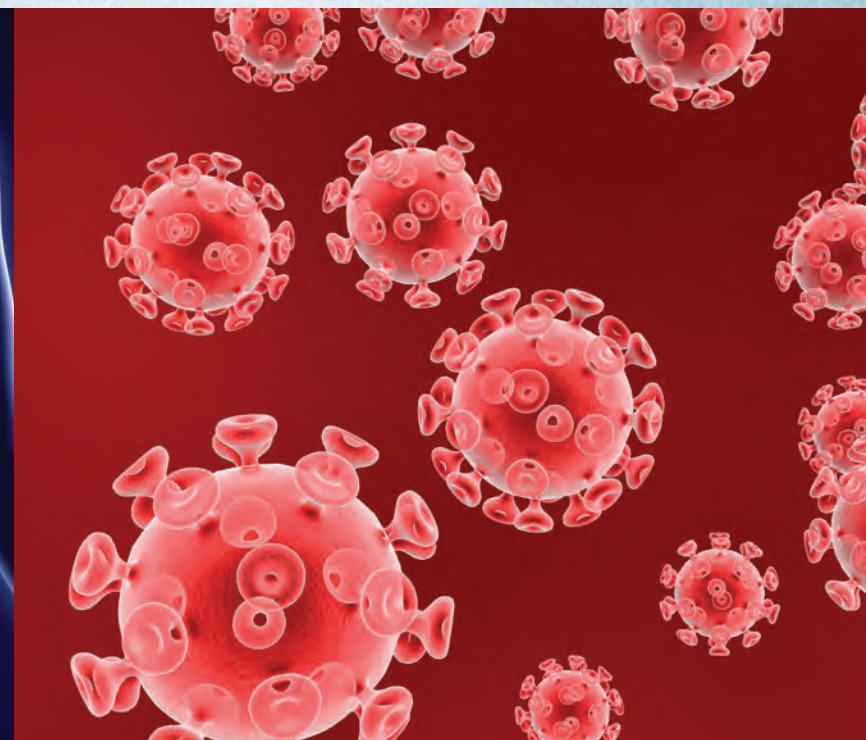
Sharon Hillier, PhD

**Sharon Hillier, PhD, and her team at Magee** involved in the Microbicide Trials Network (MTN) recently appeared in the New England Journal of Medicine with the results of "A Study to Prevent Infection with a Ring for Extended Use" (ASPIRE). This large-scale clinical trial, involving more than 2,600 women in Africa, showed that a monthly vaginal ring containing an antiretroviral drug called dapivirine was safe and helped protect against HIV. In ASPIRE, the ring reduced the risk of HIV infection by 27 percent overall, and by more than half (56 percent) in women older than 21.

In addition, in a second trial of the dapivirine ring called The Ring Study, HIV risk was reduced by 31 percent overall, and by 37 percent among participants older than 21.

"Both ASPIRE and The Ring Study have raised important scientific questions about the susceptibility of very young women to HIV, as well as their willingness to use prevention products. Further research can address these knowledge gaps. With the number of new infections in women each year, time is not on our side. We cannot lose momentum in the search for products to reduce the spread of HIV," commented Sharon L. Hillier, principal investigator of the MTN.

A follow-up open-label trial to ASPIRE is currently being planned by the MTN.



To learn more about Dr. Sharon Hillier's research into preventing the spread of HIV, see the feature story in the Fall 2015 issue of Magee Magazine.







**Steve Caritis, MD**, was awarded a five-year, \$2.8 million renewal grant from National Institute of Child Health and Human Development (NICHD) for his OB Pharmacology work, entitled "Optimization of Drug Dosing in Pregnant Women through Research and Education".



**Jonathon Shepherd, MD**, received a one-year, \$12,500 grant from The American Urogynecology Society to support his work as a part of the Junior Faculty Research Network (JFRN), entitled "The Impact of Alternative Pulse Frequencies for Initial IPG Programming on Sacral Neuromodulation Efficacy: A Prospective Blinded Randomized Crossover Trial".

**Aleksandar Rajkovic, MD, PhD**, received a five-year, \$1.7 million grant from NICHD for Magee's Women Reproductive Health Research (WRHR) training program.



**Ian McGowan, MD, PhD, FRCP**, obtained a four-year, \$1,530,000 R01 grant from NIAID entitled: "Development of a urine-based point-of-care test for adherence to antiretroviral drugs".



**Yoel Sadovsky, MD**, and his lab received a five-year, \$3.8 million R01 grant from NICHD entitled "Extracellular Vesicles and their ncRNA Cargo as Markers of Trophoblast Injury".



**Francesmary Modugno, PhD, MPH**, is the site principal investigator on a \$590,000 R01 grant from NCI entitled: "Novel Immunological Biomarkers in Ovarian Cancer Prognosis".

**Lisa Rohan, PhD**, obtained a two-year, \$250,000 grant from the FDA, entitled "A Biorelevant Dissolution Method for Particulate Dosage Forms in the Periodontal Pocket".



**Pam Moalli, MD, PhD**, was awarded a five-year, \$3.1 million R01 grant from NICHD entitled: "Porosity and tensioning: critical factors to consider when choosing a prolapse mesh". She also received a \$270,000 DOD grant entitled: "Elastomeric Auxetic Urogenital Meshes: Exploring alternatives to knitted polypropylene".

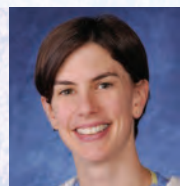


**Elizabeth Krans, MD**, was awarded a one-year, \$325,000 grant from Merck for her work entitled "A randomized clinical trial to compare the effect of immediate postpartum Nexplanon placement versus standard postpartum contraceptive care on consistent contraceptive use and rapid repeat pregnancy in opioid dependent pregnant women".



**Beatrice Chen, MD, MPH**, received a two-year, \$427,000 grant from Family Health International to study 360 Copper IUD compared to ParaGard copper IUD in nulliparous women.

**Francesca Facco, MD** was awarded a one-year, \$50,000 grant from UPMC-UPP for her work entitled "A program to improve sleep quality and glycemic control in women with gestational diabetes".



**Katherine Himes, MD**, received a one-year, \$50,000 grant from UPMC-UPP for her work entitled "Development of a Tool to Support Shared Decision Making between Clinicians and Families Facing Periviable Delivery".

**Faina Linkov, PhD, MPH**, received two grants, \$25,000 and \$8,000 from the Beckwith Foundation for her work on Development of Patient Educational Tools for Minimally Invasive Hysterectomy Decision-Making, and clinical transformation.





**June 12, 2016**

**Kids and Critters: Annual NICU Reunion**  
**Where:** Pittsburgh Zoo & PPG Aquarium, Pittsburgh, PA  
 Presented by Giant Eagle

Proceeds benefit the neonatal intensive care unit at Magee  
[www.bidpal.net/2016nicureunion](http://www.bidpal.net/2016nicureunion)

**June 26 and 27, 2016**

**8th Annual Noah Angelici Memorial Golf Outing**  
**Where:** Mystic Rock at Nemaquin Woodlands Resort, Farmington, PA.

Proceeds benefit the Center for Advanced Fetal Intervention at Magee  
[www.noahshouseofhope.com](http://www.noahshouseofhope.com)

**July 16, 2016**

**Aiden J. Strack Golf Classic**  
**Where:** Indiana VFW, Indiana, PA

Proceeds benefit the neonatal intensive care unit at Magee  
[www.aidengolf.com](http://www.aidengolf.com)

**Aug. 25, 2016**

**Savor Pittsburgh: A Celebration of Cuisine**  
**Where:** Stage AE, Pittsburgh, PA

Proceeds benefit prematurity patient care and research at Magee.  
 See ad on next page for details.  
[www.savorpgh.com](http://www.savorpgh.com)

**Sept. 15 and 16, 2016**

**5th Annual WCRC Fly Fishing Classic**  
**Where:** HomeWaters Club, Spruce Creek, PA

Proceeds benefit the Women's Cancer Research Center at Magee-Womens Research Institute.  
[www.mageewomens.org/flyfishing](http://www.mageewomens.org/flyfishing)

**Sept. 28 and 29, 2016**

**Home Depot Clays for the Cure**  
**Where:** Seven Springs Sporting Clay Lodge, Seven Springs, PA

Sponsored by Home Depot and proceeds benefit A Glimmer of Hope Foundation in support of premenopausal breast cancer research at Magee-Womens Research Institute.  
[www.symbolofthecure.com](http://www.symbolofthecure.com)

**Oct. 2016**

(check website for exact date)

**Bid for Hope XIV**  
**Where:** Off the Hook, Warrendale, PA

Mix, meet and mingle with former Pittsburgh Steelers Heath Miller #83 and many of his current and former teammates while enjoying an auction with items to please everyone.  
 Proceeds benefit A Glimmer of Hope Foundation in support of premenopausal breast cancer research at Magee-Womens Research Institute.  
[www.symbolofthecure.com](http://www.symbolofthecure.com)

**Oct. 21, 2016**

**Triple Indulgence**  
 A Jewelry, Wine & Chocolate Evening  
**Where:** Rivers Casino Grand Ballroom, Pittsburgh, PA

Join Jerome Bettis and other celebrities for a night to honor Jerome's mother, Gladys, who was diagnosed in 2014 with breast cancer. Presented by Orr's Jewelers.  
 Proceeds benefit breast cancer patient care and Magee-Womens Research Institute & Foundation.  
[www.bidpal.net/tripleindulgence](http://www.bidpal.net/tripleindulgence)



**11<sup>TH</sup> ANNUAL**

**savor**  
 Pittsburgh  
*A Celebration of Cuisine*

**Pittsburgh's culinary competition of the year, Savor Pittsburgh: A Celebration of Cuisine** is an elegant evening of culinary delights, signature cocktails, and dancing in support of Magee's fight to end premature births. At Magee, dedicated physician-scientists are working diligently to find answers to reduce premature births. Your sponsorship of Savor Pittsburgh will advance their work and help give babies a healthy start in life.

**Thursday, August 25, 2016**  
 @Stage AE

**VIP Party 5:30-6:30 p.m.**  
**Presale VIP Party \$125**  
 (\$150 after June 30)



**General Admission 6:30-10 p.m.**  
**Presale General Admission \$60**  
 (\$75 after June 30)

For more information, to purchase tickets, or to make a donation, visit [www.savorpgh.com](http://www.savorpgh.com) or call 412-641-8950.



Presented by



UPMC HEALTH PLAN

In Support of



MAGEE-WOMENS RESEARCH INSTITUTE & FOUNDATION





**MAGEE-WOMENS**  
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## Three ways to give. So many lives to touch.

Making a planned gift to Magee-Womens Research Institute & Foundation is easy. Plus this is a gift that costs you nothing today, and creates a meaningful legacy that touches the lives of so many others in the future.

- 1 Bequest** – You can remember Magee through your will.  
.....
- 2 IRA** – Name Magee as a beneficiary on your retirement account.  
.....
- 3 Charitable Remainder Trust** – Create an income stream for your life while also making a gift to Magee.



There are many other gift options to choose from including bequests, gifts of real estate, and gifts of stock. For more information about making a meaningful gift to Magee, please contact Arthur Scully at [ascully@magee.edu](mailto:ascully@magee.edu) or 412.641.8973.