

Summer 2018



Riding for More *Victories!*

Janice's victory over brain cancer inspired her to give back to others fighting.

It's a good thing Janice takes headaches seriously.

One spring day in 2012, she woke up with a horrible one. Because her mom had suffered a brain aneurysm at a young age, Janice paid attention and called her husband. By dinnertime that day, she was coming out of brain surgery.

It was stage 4 glioblastoma. A fist-sized tumor had ruptured in her brain and caused that headache that would change everything. Under the care of Lazlo Mechtler, MD, FAAN, FASN, Chief of the Department of Neuro-Oncology at Roswell Park, she did 33 rounds of chemotherapy and radiation, followed by a clinical trial.

After a recurrence and subsequent treatment in 2016, Janice is now doing so well that she's riding the 3-mile Family River Route in The 2018 Ride For Roswell. She'll be riding with Team Grey Matters, led by her sister, Michelle, and named for the foundation Janice created in order to fundraise in support of brain cancer issues.

Hear My Voice

When Janice had her last chemo treatment, she thought it would be really great if there were a way for people to celebrate their victories at Roswell Park. So she started exploring. After hearing about some things other hospitals do, she worked with her husband and son to create something everyone at Roswell Park now knows well: **the victory bell.**

Their generous donation has since become a triumphant rite of passage for hundreds, even thousands, of patients. Since 2014, survivors have rung the victory bell on the last day of their treatment, after receiving good news from their care team or when they are declared cancer free.

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Families with a history of ovarian cancer can contribute information, blood samples or both to the Familial Ovarian Cancer Registry. The registry's goal and purpose is to maintain the world's largest source of genetic data and family history profiles for research and to find better methods for detecting, treating, curing and eventually preventing familial ovarian cancer.

SURPRISING DISCOVERY ABOUT OVARIAN CANCER BRINGS *Hope* FOR FUTURE TREATMENT

RESEARCH WAS MADE POSSIBLE BY DECADES OF DONOR FUNDING

Donations to Roswell Park have enabled a potentially critical discovery in the elusive disease that is ovarian cancer. Thanks to multiple lines of donor funding, a team of researchers has discovered that transmission of a previously unknown gene mutation may play a role in women's risk of developing ovarian cancer. And that transmission comes through their fathers.

Often called the silent killer because of its nebulous, evasive symptoms, ovarian cancer is too often discovered at advanced stages. According to the American Cancer Society, the average five-year survival rate for women with ovarian cancer is 45%. It is the eighth most common cause of death from cancer and the most fatal gynecological disease.

What the Roswell Park team learned is that ovarian cancer risk is greater on the father's side of the family than on the mother's because of a gene on the X chromosome called MAGEC3. Men have only one X chromosome. So if the one they inherit from their mother has a mutated

MAGEC3 gene on it, they'll definitely pass that mutated gene on to any daughters they have.

When the gene is whole and normal, it is thought to be protective against tumor formation. But when mutations occur, cancer can result.

The team — led by Kevin Eng, PhD, Associate Professor of Oncology, and Kunle Odunsi, MD, PhD, FRCOG, FACOG, Cancer Center Deputy Director and Professor and Chair, Department of Gynecologic Oncology — was able to make this discovery thanks to a registry of information and blood samples that has been growing for more than 37 years at Roswell Park. The Familial Ovarian Cancer Registry began collecting family information and lifestyle data from families with a history of ovarian cancer in 1981. More than 50,000 people from more than 2,600 families have contributed. It is made possible by donations not only from generous friends of Roswell Park but also from qualified families across the country who share their experience with the disease.

When researchers began examining registry data on families whose information included both grandmothers and granddaughters, they found that for women with a paternal grandmother who'd had ovarian cancer, there was a 28% rate of disease occurrence, but only a 13.9% rate when it was the maternal grandmother. This highly suggests that the X chromosome was involved. Further deep sequencing of the X chromosome of registry members uncovered a previously unknown mutation in the MAGEC3 gene.

Women who have this mutated gene may also have earlier onset of the disease. And it also appears that the mutation may cause cancer in men in these families — especially prostate cancer.

The study that arose from this data analysis also was supported by funding from generous Roswell Park donors. The project was one of 12 to be chosen for a grant from the Scientific Advisory Committee (SAC) in March 2017. SAC meets twice a year to review funding applications from Roswell Park researchers and selects those that show the most promise of making a difference in the fight against cancer. It distributes about \$1.5 million during each round of submissions. 100 percent of these funds comes from donations to the institution.

Dr. Eng is already getting calls from fathers concerned about what this means for their daughters. "Those are the kinds of questions we need to figure out how to answer next," he says.

"While it's important, it's early days yet," says Dr. Odunsi. "It needs to be validated in a larger population of patients from ovarian cancer families. If the findings hold true, this will be very significant because of the potential to develop vaccines against this mutation and eventually prevent ovarian cancer from developing in the first place in people who show the genetic mutation."



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— Dr. Odunsi

“THIS RESEARCH GROUP WOULDN'T BE POSSIBLE ANYWHERE BESIDES ROSWELL PARK. The registry is here. It's been around for a long time. People are partnering with it nationally and internationally. It's a fantastically important resource. And it would not be possible without the support of donations. The Familial Ovarian Cancer Registry is supported almost 100 percent by donor dollars. ”

— Dr. Eng



HELPING KIDS feel better

Donor support enables complementary & integrative medicine and nutritional counseling for our pediatric patients



NUTRITION EDUCATION

Studies have shown that as much as 70 percent of our cancer risk arises from diet or lifestyle. The Integrative Medicine Program teaches young patients and their families about eating in a way that promotes healing and helps diminish the effects of cancer treatments. Children even get to interact directly with chefs in live demonstration events, which gets them excited about healthy food and how to prepare it. And families learn how to select and prepare foods in ways that fit their budgets.



At Roswell Park, cancer treatments advance and improve greatly year by year. But treatment too often comes with an unpleasant price: debilitating side effects like pain, headaches, nausea, fatigue, anxiety and more.

Thanks to donor support, Roswell Park has launched a new Integrative Medicine Program to begin alleviating these problems for our youngest patients. Led by Kara Kelly, MD, Chair of Pediatric Oncology and the Waldemar J. Kaminski Endowed Chair of Pediatrics, and Program Manager Doug McDaniel, MTOM, LAC, it utilizes complementary and alternative medicines (CAM) such as acupuncture, massage and reflexology as well as nutritional counseling to support the whole person and to eliminate or alleviate some of their discomfort.

These noninvasive approaches have been proven to relieve and even eradicate many symptoms brought on by chemotherapy, surgery, radiation and prescription medications. CAM can reduce the need for pain medications or reduce their doses, reduce headaches or anxiety, improve energy and so much more. And Roswell Park is providing them all right now to pediatric patients free of charge, thanks to the generosity of donors like you.



“CAM is the missing piece of the puzzle. It’s that piece that we need because conventional medicine is geared to treat disease, and it does it very well, but there aren’t a lot of interventions for supporting the person. That’s where I come in; that’s where this program comes in. We’re all about supporting you.”

— Doug McDaniel, Program Manager



RESEARCH WITH FAR-REACHING IMPACT

Research will be key to achieving the goals of the Integrative Medicine Program and will be included in many treatments. For instance, Dr. Kelly’s team will conduct pre-and post-session evaluations of their yoga and meditation courses, using the data collected to adjust the program as needed and to reinvest in it.

The research performed throughout the program should produce hard data proving the success of CAM therapies in treating debilitating side effects and substantiating their expanded use into the adult patient population. It also will support the development of the Roswell Model, which other institutions will seek to replicate, with great potential for having real impact on pediatric programs across the nation.



Emmett (left) and Ahabya (right) pose with Rachel Simson, a Clinical Dietitian, while filming a segment for an upcoming health & nutrition video series. Watch for it on Roswell Park’s social media channels.

“It’s very encouraging that we have these options at Roswell Park. It’s definitely something that, because it is being provided by donors, it’s not another expense that we have to worry about.”

— Jen, mother of Stella, acute lymphoblastic leukemia patient



Giving Voice to Our Stories

Hubbell Family Gift Provides Special Opportunity for Roswell Park Community

LIFE RECORDED

A Project Inspired by StoryCorps

We all have a story to tell.

A cancer diagnosis — whether your own or a loved one's — makes you stop and think. It can change the way you think of yourself and your life, your family, your friends. Since 2014, Life Recorded has given individuals connected to Roswell Park the chance to record and preserve a moment in time, reflect on days gone by, talk about dreams for the future and express gratitude to loved ones.

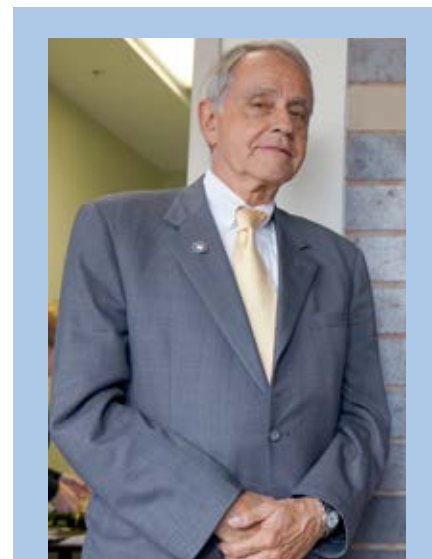
The project was introduced to Roswell Park thanks to Phil Hubbell, whose wife sought care here for breast cancer. Despite the severity of her illness, there were still many things she wanted to do, say and share as she lived with the cancer.

"The saddest I can remember my wife being was when she would talk about wanting to tell the story of her life and all our travels together for the grandkids to know about when they got a

little older," says Phil. "She knew that she was weakening, and she didn't have the wherewithal to write it down. So my daughter suggested we do a video, and it brought her such joy in fulfilling this dream of hers to let her story be heard."

Phil was so moved by his wife's experience that when the chance arose, he made a gift to support a similar project out of Roswell Park's Pastoral Care Department.

A generous donation from the Jayne and Phil Hubbell Family brought StoryCorps Legacy to the institution. Soon, it transformed into Life Recorded: A Project Inspired by StoryCorps. StoryCorps is an organization that records and preserves stories in an archive at the Library of Congress, and StoryCorps Legacy is an offshoot specifically for people with serious illness. StoryCorps Legacy spent several days at Roswell Park teaching selected staff how to be story facilitators.



From research to the patient art cart to Life Recorded, the Hubbell Family has supported Roswell Park with thoughtful gifts since 1991.

Roswell Park's Quality of Life Fund is supported by the Ralph C. Wilson Jr. Foundation and the generosity of our donors.



The storytelling opportunity offered by Life Recorded is open not only to all patients, but to caregivers, family members, doctors, nurses, blood donors, Ride For Roswell participants, volunteers — anyone with a Roswell Park link. Your story can be about a cancer journey or a life journey or a relationship. And you decide how you share your audio or video recording: with everyone, with a few people, or with no one but yourself and your professionally trained facilitator.

"The act of telling one's story can be cathartic, as so many of our participants have reported. And when times get tough, there's no better way to show yourself that you can survive again than hearing yourself tell the story of your self surviving," says Alicia Larson, Coordinator of Life Recorded.

What message would you record for others to hear?

Call Roswell Park's Pastoral Care Department at 716-845-8051 to learn more or to schedule your recording and a pre-recording discovery session.

"When I recorded my story last year, my son, who's a communications major, asked me the questions. The biggest impact for me was having the opportunity to tell my story through his questions — and how much it brought us together. But it was also important to me to help others see how much hope there is."

— Jeffrey, 17-year testicular cancer survivor

Helping Ella Feel Like a Kid Again



"With Ella being affected by such a scary disease, it's a dark time for our family. When we learn of the people who are helping us and are helpful to anyone who has such an illness, their kindness and generosity mean the world to us. When you're put in this situation, you can't think straight, and you can't think of everything that will make it better. I hope that they know how important their efforts are to people."

— Mary, Ella's mom

Ella was diagnosed with acute lymphoblastic leukemia just this February. Three days after her diagnosis, she had her 10th birthday. It was supposed to be a very different kind of day. A day to celebrate, to be excited about entering double digits.

Instead, Ella began chemo on her birthday. Too soon, her hair started coming out in piles when she combed it. "She would cry and say, 'Would you cover the mirror in here so I don't have to look at myself?'" says her mom, Mary.

That's when Martha Hickey stepped in. She's Coordinator of Roswell Park's Resource Center and Wig, Hat and Scarf Boutique, where anyone undergoing cancer treatment can come to select a wig, scarf or hat free of charge thanks to donations to Roswell Park. Visitors also receive compassion, comfort and support from the Center's staff and volunteers.

"When Ella's mom came into the Resource Center with Cate, a Pediatric Oncology Psychologist at Oshei Children's Hospital, I connected with them immediately," Hickey says. "Mary was worried and needed a compassionate response and a good solution to help Ella. I told her, You've come to the right place. We can certainly help your daughter feel more like herself."

Martha matched Ella's hair color from swatches and sent Mary back to Ella with a bag full of wig and hat options. "Feeling good about appearance is very important, especially to children undergoing cancer treatment," Hickey says.

"It's a humbling experience fitting wigs for our patients receiving cancer treatment. It is a special opportunity to make a personal connection with a patient in a nonclinical way."

Hickey's expertise and support were just what Mary needed at that moment. "Martha was like an angel sent from above on a dark day," she says.

Ella picked a wig she liked. Hickey put a rush on the order so it would arrive the very next day. Hickey had Ella's other choice, a hat with hair attached to it, already in stock.

"Ella wears it every single day," her mom says. "It worked out perfectly. It looks exactly like what her hair normally looks like. You really couldn't tell that she doesn't have any, and that makes her feel a lot better."

"Making Ella feel like a beautiful princess with long blond hair was the goal, and we accomplished it!" says Hickey.

"It makes me feel like a real kid again," says Ella.

Last year, your support allowed the Resource Center to give out more than 1,500 free head coverings to patients battling cancer. In addition to the services of the Wig, Hat and Scarf Boutique, the Resource Center provides information and expertise on all aspects of cancer to patients and their loved ones. It is supported solely by donations.

Elm & Carlton Streets
Buffalo, NY 14263
716-845-4444
RoswellPark.org/Giving

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And every single person within hearing range cheers when they hear it sound.

“Because I’m a pianist, sound is important to me,” Janice says. “This bell has a beautiful tone. There are warrior angels on it and a Latin saying that means ‘Who touches me hears my voice.’”

Janice would rather be sitting at a piano than most other places. She’s a church pianist, and has just written four inspirational songs she’s recording with the help of a local choir and one of her nurses, who’s a guitarist. “To me, music is a therapy,” she says. “I feel it really helps people.”

Why Ride?

The average life expectancy after receiving a diagnosis of stage 4 glioblastoma is two years. Janice is riding in The Ride For Roswell six years after her cancer was discovered. She is deeply grateful to Roswell Park and all its donors for all they do to help people.

“Roswell is just fantastic. What a great institution. The people there are just phenomenal, and the way they do things and the way they help you — we had a

makeup class for people with cancer. That was really nice and really helpful. They help you feel better about it, and the expertise there is just amazing. Here’s Buffalo, which is not a great big city, having this incredible institution right here in our backyards. It’s amazing.”

Janice can’t ride a regular bike anymore because of a bad blind spot resulting from her first brain surgery. So her husband got creative and joined a men’s and a women’s bike together side by side. It’s a tandem built with love that the two of them will ride on June 23.

So, what does The Ride mean to Janice?



Janice Trudnowski with her husband, Mike

“It’s that I am somebody who has brain cancer, and I am a person who is strong enough to be able to be out there riding and showing people that you have cancer and life doesn’t stop with that diagnosis. That’s what it means to me, and I want to encourage people to live their life as fully as possible.”