

Donor Dollars at Work

Winter/Spring 2016

Finding Hope: Cheryl's Journey with Ovarian Cancer



Cheryl Reinhardt was one of the first patients to receive a new treatment that was developed with critical support from your donations.

Francis Reinhardt was just 48 years old when she was diagnosed with ovarian cancer in 1980.

"She had never been sickly, but she had begun not feeling well, and she finally decided to go to the doctor," Francis's daughter, Cheryl, said. "She was told she had one week to live."

Just one week later, Francis passed away.

"We were in shock. It just happened so fast," said Cheryl. "My brother was only 16, and it was very difficult for both of us."

Thirty years later, Cheryl was diagnosed with stage IV ovarian cancer herself. She was 48 years old — the same age her mother was when she was diagnosed. Cheryl assumed she, too, would only have one week left to live.

"I quit my job. I thought, 'this is it. If I only have one week to live, why work?' I just started to mentally prepare," said Cheryl.

After her initial diagnosis, Cheryl came to Roswell Park Cancer Institute (RPCI) for a second opinion, and met Kunle Odunsi, MD, RPCI's Deputy Director and Chair of Gynecological Oncology.

"My attitude immediately changed when I came to Roswell Park," said Cheryl. "When I first met Dr. Odunsi, he told me, 'I know what to do,' and even though I wasn't sure what would happen, I could sense that I was in good hands."

Cheryl underwent surgery and chemotherapy, and went into remission shortly after. But, eight years later at a checkup, the doctors found another tumor.

"I went outside, and pulled out every weed in the front of the house because I was so angry," she said. "I mustered up everything I could, and I told myself, if you got through it the first time, you can do it a second time."

After a few more rounds of chemotherapy, Dr. Odunsi asked Cheryl if she would be willing to participate in **a clinical trial for a new, groundbreaking treatment that had been developed by Roswell Park scientists with critical support from your donations.** This new treatment — an ovarian cancer vaccine — works by stimulating the immune system in the fight against cancer.

Having already experienced the unpleasant side effects of chemotherapy and hopeful for a promising alternative treatment, Cheryl agreed to join the trial. Today, 12 years after her initial diagnosis, she's back in remission and doing well.

"I didn't expect to live for five years, and according to the statistics, I shouldn't be here," said Cheryl. "But I am, and I really believe it's because of the new treatments I was able to receive. Now, I don't take anything for granted."

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Transforming the Mood, One Song at a Time



Greg Barresi plays some tunes with RPCI patient Alex Soper as part of the Arts in Healthcare program, which is funded entirely by your donations.

Seven-year-old Lucas Leitzan is hanging out in his Roswell Park hospital room with his parents, Melissa and Mark, when an unexpected visitor arrives. It's Greg Barresi, the hospital's new musician-in-residence, carrying a guitar and an assortment of handheld instruments: egg-shaped maracas, a tambourine, a stick with jingle bells attached. Greg invites the family to join in a spur-of-the-moment songfest, and they perk up at the suggestion.

"Do you play an instrument?" Greg asks Lucas.

"He's a natural-born drummer," Mark offers, so Greg hands Lucas the tambourine and a couple of egg shakers and shows him how to use the tambourine like a drum.

"What kind of song should we do?" asks Greg. "Something fast? Something slow?"

Lucas grins. "Something slow," he decides, adding, "I like every song."

So they start off with Bob Marley's "Three Little Birds." Don't worry 'bout a thing, 'cause every little thing gonna be all right...

It's a good intro. The tempo picks up with Hank Williams' "Jambalaya," and by the time they launch into Percy Mayfield's "Hit the Road Jack," Lucas is rocking the hospital bed, his head bobbing back and forth, one hand thumping the tambourine, the other keeping time with an egg shaker. Nurses peek through the observation window, all smiles at the raucous activity. Another pauses in the doorway, her foot tapping and hands clapping.

That's typical of what happens when Greg visits clinics and inpatient rooms bearing the gift of music. **He's one of six part-time Artists-in-Residence who visit RPCI each week as part of the Arts in Healthcare program, which is funded entirely by your generous donations.** The initiative uses the visual and performing arts to promote physical and emotional well-being among patients, visitors and staff.

It works: the arts have been shown to "reduce anxiety, depression, pain and fatigue and increase quality of life in patients with cancer," according to a study published in JAMA Internal Medicine.

Every time he visits, Greg sees firsthand how music transforms the hospital environment. "Often it changes the mood — maybe in just one room or maybe in the whole hallway. People hear someone having a good time in the room next door and it makes them want to join in the fun.

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"That's always my goal, to get people involved and engage them beyond just listening." He does that partly by offering the handheld instruments — "things people aren't generally intimidated to play."

Greg has a broad repertoire and takes requests, but usually he skips songs "that might be too nostalgic or that carry a lot of emotional weight," to avoid triggering sad thoughts or fears. So when older patients ask for tunes by Johnny Cash, he obliges with the snappy, upbeat "Get Rhythm." He gets a lot of requests for Beatles hits, too.

"With the really young kids, all the classics are still in high demand — your 'Old McDonalds' and your 'Itsy-Bitsy Spiders'," he says. But no baby songs for Lucas! When Greg teasingly suggests "Twinkle, Twinkle, Little Star," the reaction is strong and swift: "No, no!" He'd rather hear something from the '40s. Lucas requests another 200 songs, but there's time for only one more, so he puts his heart and soul into "It Don't Mean a Thing If It Ain't Got That Swing." He forgets the mediport in his chest and the IV pole next to the bed. He sings out the refrain — "Doo-wop! Doo-wop!" — and adds a theatrical flourish with his arms. He grins, swept up in the joy of the music. He pounds the tambourine till it dances.



Carly's Club Gives the Joys of the Holiday Season to Children with Cancer

Between doctor's appointments, chemotherapy treatments and dealing with debilitating side effects, it's difficult for children with cancer to have fun and just feel like a kid. Stella Usiak, a 12-year-old leukemia patient, knows just how hard it can be.

"The past few years have been very crazy, and there have been lots of bumps in the road," she said. "I haven't been to school in two years, and I really miss being around my friends."

Stella was first diagnosed with cancer at the young age of 7, and has undergone chemotherapy, radiation, and most recently, a bone marrow transplant. Somehow, she's been able to stay optimistic through it all.

"I try to keep as positive as possible, because that's the only way I'm going to get through it," she said.

Stella says there have been a few things that have helped her through her journey: her family, her favorite music and the friends she's met through Carly's Club. **Funded entirely by your donations and fundraising events like Summer Splash and Carly's Crossing, Carly's Club offers supportive programs for young Roswell Park patients and their families.** Because of Carly's Club events, children with cancer like Stella can meet other kids who are facing similar struggles.

"My friends at school encourage and support me, but they don't really understand what I'm going through," Stella said. "But I can talk about cancer with my friends at Carly's Club, and they just get it."

Carly's Club's largest event is an annual holiday party held in December for hundreds of children and their families. Because of your support, the kids are able to enjoy dinner, dancing, arts and crafts, and meet their favorite cartoon and movie characters, like Olaf from Frozen and Chewbacca from Star Wars. All the children and their siblings receive a gift off their wish list from Santa Claus, thanks to generous community members who donate hundreds of presents each holiday season.

"This is a place where I can have fun and forget that I'm not a normal kid, and that I can't do some normal things, like ride a bike and go to school," Stella said at this year's party.

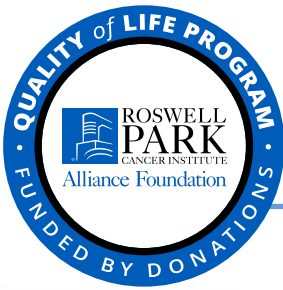
The chance to celebrate the season is a treat for the parents, too, who enjoy the escape from the hospital and the realities of their child's cancer journey.

"Tonight is one of the best nights for all of the parents who are here," Jen Usiak, Stella's mom, said. "We get to see our children thrive, be happy and just be little kids — like they're supposed to be."



The holiday party is just one event that Carly's Club puts on for its members. Throughout the year, Carly's Club hosts dozens of fun, diversionary events, from a summer picnic, to bowling nights and spa parties. Thanks to your generosity Carly's Club is also able to offer critical services to young patients and their families, including counseling, caregiver support programs, a stocked in-patient kitchen and therapeutic play programs.

Monies raised by Carly's Club also fund groundbreaking pediatric cancer research at Roswell Park, allowing researchers to advance their cutting-edge ideas and work toward creating a world where no child has to deal with this disease.



Quality of Life Q & A:



Many individuals who are battling cancer are going through one of the most difficult times of their lives. To help ease their cancer journeys, Roswell Park provides essential quality-of-life programs that lend an extra helping hand, give emotional support and provide creative, enjoyable outlets to patients and their families.

But in order to provide these programs, the Institute needs resources — and that's where you have stepped in. In August, your support allowed Roswell Park to award \$655,000 to 27 quality-of-life programs to meet patients' social and emotional needs.

Staff members who help manage these programs witness the positive impact your donations make on our patients' lives every day.

WIG AND HAT BOUTIQUE

with Megan Battaglia, Sr. Education Facilitator

Q: How do these wigs and hats help patients?

Megan: Many cancer patients undergoing treatment lose all or some of their hair. It is a visible sign of their illness that can have a devastating effect on their self-esteem at a time when they do not feel well and are already scared. The wigs and hats give them a chance to regain a sense of normalcy, and to look and feel better about themselves.

Q: Why is support from donors necessary for this program?

Megan: Without the generosity of our donors, the wig and hat program would not exist at its current level.

The Resource Center currently does not have a budget allocated for this quality-of-life service that our patients have come so much to appreciate. Drawing more traffic to the Resource Center also provides us with additional opportunities to get to know our patients better and connect them with other helpful services and resources.

Q: What kind of reactions have you seen from patients and their families when you tell them that these items are available?

Megan: They are surprised and thrilled, and many cry. The loss of hair is so emotional for both women and men. Those who were told about the program are happy to be able to pick out a wig at no charge, although some still try to pay or make a donation. The patients who just happen to come into the Resource Center and see the wigs on display often ask if we sell them — and when they find out about our program, they are overjoyed.

Q: What would you say about this program to someone who is considering donating but isn't yet convinced?

Megan: I believe it is important for donors to realize that this program is about so much more than just a free wig. When a patient finds out their cancer treatment will result in hair loss, it becomes an extremely emotional issue. Hair loss is the outward sign of their disease and it makes it harder for them to live a "normal" life, as they tell us. This is our opportunity through the wig program to offer kindness, understanding and empathy.

Q: From your perspective, what is your favorite part about this program?

Megan: Without a doubt, my favorite part of the program is getting to know the patients so personally. By being able to spend private time with them and by offering kindness and truly listening, I believe we can help them feel how much we care and want to provide them with positive experiences during their treatment.



How Your Donations Give Comfort and Support to Patients

Donations also support Roswell Park's End of Life and Bereavement program, which provides compassionate support for patients who have received a terminal diagnosis, as well as their families. This initiative has been supported by donations since its founding in 2002, and since then, the program has reached out to 12,000 patients and their families.



END OF LIFE AND BEREAVEMENT PROGRAM

with Beth Lenegan, PhD, Director of Pastoral Care

Q: What does the End of Life and Bereavement program provide to patients and their families?

Dr. Lenegan: When a patient receives a terminal prognosis of six months or less, our staff contacts the patient and explains what our program does, and that we would like to help during this difficult time. If they are interested in the service, a trained pastoral care provider keeps in touch with the patient and their family, and offers them support.

When the patient passes away, we give whatever support is needed — we may go to the wake or help organize a funeral service. We then stay in touch with the family for one year and offer our bereavement services to the family.

Q: What bereavement services are available for families when their loved one passes away?

Dr. Lenegan: Donations provide the funding for patient remembrance services that we hold throughout the year. These interfaith memorial ceremonies celebrate the lives of individuals who have passed away. Family members, friends, and colleagues gather for a beautiful service that honors the lives of so many who have been touched by cancer, and the evening is filled with song, prayer and the message of hope.

We also hold a monthly grief support meeting for families at local churches and meeting places, so that they can talk about their loss with others who understand what they are going through. And from care notes, to phone calls, to holiday cards, we stay connected with the families to offer support and help when we can. Donated funds have also helped us create our own grief resource book that is provided to all of the families that we are helping, and we send out a grief holiday book to each family who has lost a loved one, because we know it is a difficult time of year for them.

Q: How does this program help patients and their families?

Dr. Lenegan: Each patient gets something different out of this program. Some are trying to figure out why this is happening to them, others may have questions about the afterlife — and they might just need someone to talk to about their thoughts.

The bereavement aspect of the program reminds families that we have not forgotten them or their loved one. It allows us to say, 'we are here to continue our support of you.' The remembrance services and grief program are a comfort to them, and the support groups allow families to meet others who are going through loss as well. There is a common bond there.

Q: How are donations helping the program grow?

Dr. Lenegan: This year, we are expanding our grief support programs to the suburbs, including Niagara Falls and the Albion area, to help more families who may not want or are unable to travel into Buffalo, especially in the winter months. We hope that we will be able to help more individuals and give them as much support as we can. We are also planning our first overnight retreat in May for families to talk about their grief and the impact it has on their lives.

Q: Why should donors care about this program?

Dr. Lenegan: We have all lost a loved one, and we know how difficult coping with loss can be. Some of us have also experienced the emotional challenges in providing support to someone who is facing the end of his or her life. When we think about our own experiences, we know how important sympathy and understanding is during such a difficult time. Because of this program, we are able to give some comfort and solace to those who are grieving, and donors should feel good knowing that they play a vital role in making these services available to our patients and their families.

Four New Research Projects

JUMPSTARTED

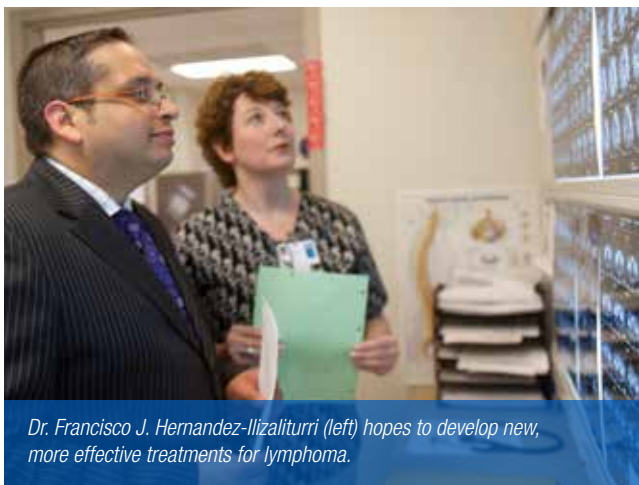
By Your Donations

Many of the world-class researchers at Roswell Park have new, innovative research ideas that could change the course of cancer treatment and help save lives. But, without funding, their ideas would never get off the ground.

Your support provides the critical funds that allow scientists to start new initiatives each year. In December, four researchers received funding from your donations to start new projects. These researchers applied and competed for the funds as part of a review process that takes place twice per year. A Scientific Advisory Committee, made up of objective Roswell Park staff and faculty, reviewed the applications and scored them based on their ability to find cancer cures and save lives. This process ensures that your donations are put to the best possible use to fund the most promising research projects.

Innovative, preliminary projects like the four that were recently funded often lead to long-term funding from national organizations, as well as new treatments. Below, the four scientists explain what their projects will explore and how they will contribute to the fight against cancer.

HEAR FROM THE RESEARCHERS



Dr. Francisco J. Hernandez-Iizaliturri (left) hopes to develop new, more effective treatments for lymphoma.

“ Lymphoma

Over the last 20 years, the incidence of lymphoma has been steadily increasing. Many patients become resistant to chemotherapy, and so more and more patients are losing their battle with this disease. We hope to change that. Our project will investigate a promising idea that a drug used in the treatment of diabetes could help patients who aren't responding to chemotherapy.

This initiative, funded by your donations, could lead to the development of new therapies to better treat lymphoma and help save patients' lives.”

“ Breast Cancer

African American women are more frequently diagnosed with aggressive breast cancer that does not respond well to treatment, and they are dying from the disease at higher rates than non-African American women. **Thanks to your donations, we will be able to study differences in DNA that may be causing African American women to have this more aggressive form of the disease.** This initiative, made possible because of Roswell Park supporters like you, could lead to the prevention of aggressive breast cancer and to new, targeted therapies to help save the lives of African American breast cancer patients.”



Dr. Christine Ambrosone hopes to better understand why African American women are more likely to be diagnosed with aggressive breast cancer.



Dr. Martin Mahoney aims to increase the rates of HPV vaccination so that fewer adolescents develop preventable cancers in their lifetimes.

Prevention

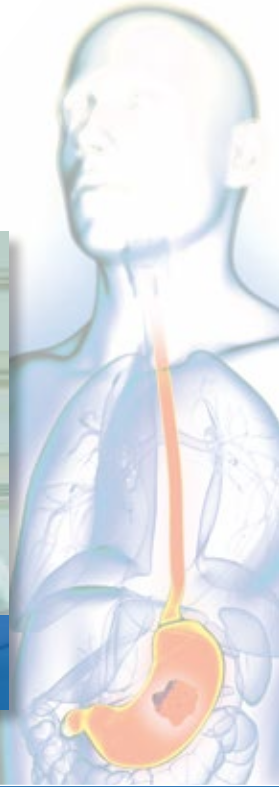
We know that the Human Papilloma Virus causes a significant number of cancers and precancers. Although there are safe and effective vaccines against this virus, the vaccination rates average at only 37% for adolescent females and 20% for adolescent males. We aim to improve those rates so that fewer adolescents develop cancer in their lifetimes. **Your gift will allow my team to identify successful strategies that medical offices use to achieve high rates of HPV vaccination.** We will use that information to develop an intervention with medical offices that have suboptimal HPV vaccination rates. This project is incredibly important, since the HPV vaccine is cancer prevention; every year that HPV vaccination rates remains low will result in thousands of adolescents developing HPV-related cancers and precancers during their lifetimes.

Stomach Cancer

Stomach cancer is frequently not found until it is at an advanced stage, and the tumors are often aggressive. Sadly, many patients lose their battle with the disease. **Because of your contributions, my team and I will be able to study molecular changes that may lead to the growth of stomach cancer.** Our findings will help set the stage for the development of new, innovative drugs that may be able to better treat the disease and have minimal side effects.



Dr. Steven Hochwald's project aims to improve the survival rates of stomach cancer by improving our understanding of what leads to the growth of the disease.



★★★★★
CHARITY NAVIGATOR
Four Star Charity

The Roswell Park Alliance Foundation, the not-for-profit that raises funds to benefit research and patient-care programs at Roswell Park Cancer Institute, recently achieved the highest possible rating from Charity Navigator, America's premier charity evaluator. The four-star rating recognizes the Alliance Foundation for sound fiscal management and commitment to accountability and transparency.

"Receiving four out of a possible four stars indicates that the Alliance Foundation adheres to good governance and consistently executes its mission in a fiscally responsible way," said Michael Thatcher, Charity Navigator President and CEO. "Approximately a quarter of the charities

we evaluate have received our highest rating, indicating that the Alliance Foundation outperforms most other charities in America. This exceptional designation from Charity Navigator differentiates Roswell Park Alliance Foundation from its peers and demonstrates to the public it is worthy of their trust."

Charity Navigator is the nation's largest evaluator of charities and its ratings show donors how efficiently a charity will use their support, how well it has sustained its programs and services over time and their level of commitment to good governance, best practices and openness with information.

"Our generous donors have a right to know that their gifts are directly funding the most promising cancer research and compassionate quality-of-life programs for patients and their families, so we are very pleased to receive this prestigious recognition and celebrate with our staff and volunteers who work tirelessly to ensure that donations are put to the best possible use," said Cindy Eller, Executive Director, Roswell Park Alliance Foundation.

(continued from cover)

How Your Donations are Helping Patients Like Cheryl

Despite recent advancements, survival rates remain poor for women diagnosed with late-stage ovarian cancer. The disease still claims 14,180 lives each year.

But Dr. Odunsi and other scientists at Roswell Park are pressing on, determined to build on their progress and develop more effective treatments to help patients like Cheryl.

In 2013, Roswell Park received a prestigious, highly competitive award from the National Cancer Institute (NCI) to further research on new therapies that use the immune system in the fight against ovarian cancer. Although the grant from the NCI covers the majority of the cost of the five-year initiative, **the project does require additional funding from Roswell Park — and that's where you have stepped in. Your donations are making it possible for RPCI scientists to continue their work on this promising initiative.**

The research involves four groundbreaking projects: three clinical trials evaluating new immunotherapies and one study looking for ways to reduce risk in women at high risk of developing ovarian cancer.

"The NCI has recognized that our research has very high potential for changing the lives of ovarian cancer patients around the world," said Dr. Odunsi. "This research is a combination of all the understandings we have built for more than a decade, and we expect we will be able to be able to improve outcomes of patients who are battling this devastating disease. **It is thanks to our supporters and donors that we have been able to progress this far.**"



Your donations are now supporting a groundbreaking ovarian cancer research project led by Dr. Odunsi, who is working to develop new treatments that use the immune system in the fight against the disease.