

Donor Dollars at Work

Fall 2017

A New Era for Pediatric Research and Care at Roswell Park



Candace S. Johnson, PhD, President and CEO of Roswell Park Cancer Institute; Chris Koch, President and CEO of New Era Cap; Stella Usiak, Roswell Park patient; Jen Usiak, Stella's mom; Chuck Collard, co-founder of Carly's Club; and Kara Kelly, MD, Chair, Pediatric Oncology, at the unveiling of the new branding at New Era Cap headquarters in Buffalo.

After 15 years of providing funding for critical pediatric cancer research and family support programs, Carly's Club has a new name and new look as the Courage of Carly Fund. This announcement came with the opening of the new Katherine, Anne and Donna Gioia Pediatric Hematology Oncology Center at Roswell Park — a new outpatient space made possible with generous donor support.

The new name was inspired by the courage and strength of every child fighting their disease who comes through our doors. Because every child deserves a fighting chance.

In addition, the New Era Cap Foundation has committed to a multi-year sponsorship of Courage of Carly programs.

"As the program sponsor of the Courage of Carly Fund, we're further ensuring that these young patients and their families have access to resources and activities that let them be kids, have carefree fun and know they're not fighting alone," said Chris Koch, President, New Era Cap Foundation.

Giving Every Child A Fighting Chance



ROSWELL PARK CANCER INSTITUTE

Carly's Club was created by 8-year-old Carly Collard Cottone, who was diagnosed with brain cancer in 1999. During her own treatment, Carly wanted to help other kids fighting cancer, and Carly's Club was born. Sadly, Carly died in 2002, but her name and legacy live on, bringing extra smiles and happiness to our youngest patients and their families.

One of those patients is Stella Usiak, a 14-year-old, two-time survivor of acute lymphoblastic leukemia still fighting the side effects of her cancer and her bone

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THE NEW *Team* ROSWELL

FUELING ADVANCES THROUGH COMMUNITY EVENTS

From its start with a pink basketball and Tim Hortons coffee can to high school hallways now so packed with baked goods and raffles that you can barely squeeze through them, Shooting for a Cure has grown by leaps and bounds to become one of the most important nights of the year to an entire community.

Shooting for a Cure is an annual Pembroke High School Lady Dragons basketball game dedicated to raising funds to fight breast cancer at Roswell Park. Begun in the small town of Pembroke, New York, in 2011 to show support for the athletic director's wife when she was diagnosed with breast cancer, now it recognizes the fights of dozens of people each year — and pays tribute to those lost.

So far the event has raised more than \$60,000 to support new advances in breast cancer research at Roswell Park, with their 2017 game bringing in \$20,000. And each year, players new and returning take up the charge. "This is the identity of the basketball program at Pembroke," says Mike Wilson, the former girls basketball coach who is still heavily involved in the charity game. "They can't wait for that game."

Mike didn't know where to begin when he and the 2011 team started Shooting for a Cure. So his father-in-law connected him with the Roswell Park Alliance Foundation. The Pembroke girls basketball team hosted their fundraising game as part of Team Cure, and Alliance staff helped make it work. Since then, the connection has grown as strong as the event.

Strong Roots for Team Roswell

Team Cure has become rooted in Western New York as a way for community members to raise funds in their own ways to support the fight against cancer at Roswell Park. This year we were excited to launch a new incarnation of this program: [Team Roswell](#).

Anyone who wants to join Roswell Park in the fight against cancer can be a part of Team Roswell and access all the support and fundraising tools it offers. [Team Roswell is the chance to turn athletic events, interests, special moments and more into funding for the next lifesaving cancer treatment.](#)

Possibly the best part of the change is the new online fundraising platform. You can create your own fundraising page on the Team Roswell site, and your donors can give right there. Donations come straight to Roswell Park, with no third-party vendors or sites involved.

What kinds of events do community members host? All kinds. You can collect donations in lieu of gifts for your birthday party; sell lemonade from a table in your front yard; or hold a yard sale, a concert or a baseball tournament to benefit Roswell Park. Do it once or make it a yearly event like Shooting for a Cure.

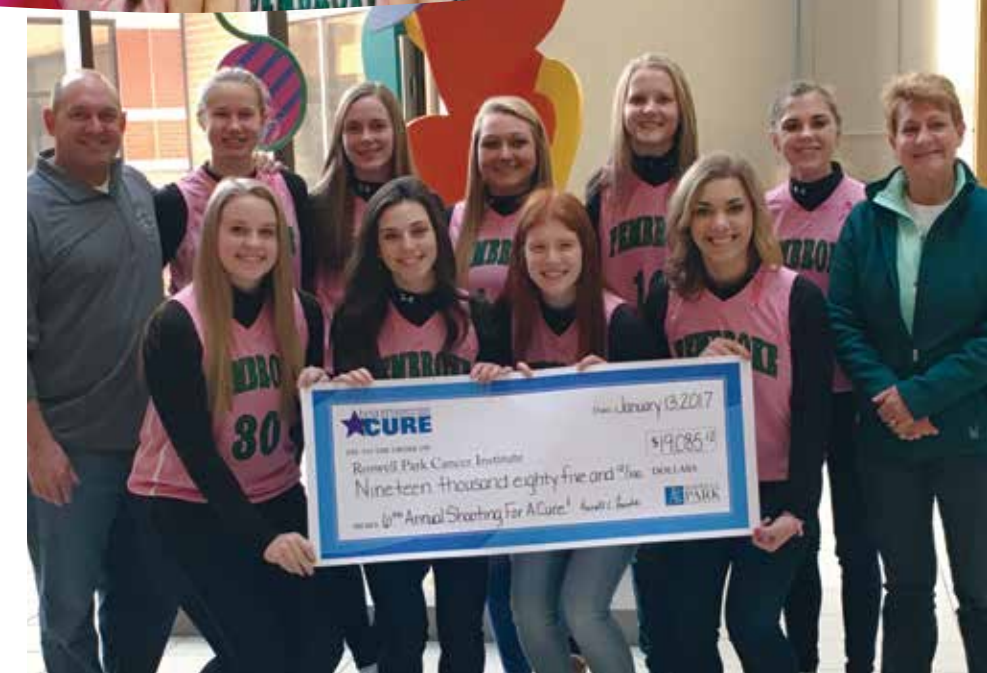
Change You Can Believe In

Mike and the students have put on the game for six years as members of Team Cure. Now, with the advent of Team Roswell, Mike sees expanded opportunities for the game and its fundraising.

"The new Team Roswell website will be vital to sharing our mission with even more people," he says. "As we embark on hosting our seventh annual Shooting For a Cure game in January, the opportunities that this new platform provides us are limitless.

"Unfortunately, cancer affects all of us," Mike points out. "The more people who get involved, the more people who step up, the more people who are passionate and believe in making a difference — the bigger the impact will be."

Donations like those from [Shooting for a Cure](#) are put to immediate use to fund promising new research. Current breast cancer research at Roswell Park includes one study exploring new applications for existing medicines and another investigating the impact of genetics on breast cancer development and spread.



“ Donations to Team Roswell events provide Roswell Park scientists like me with the seed funding to launch new projects that can make real-life differences for many patients. The seed funding enables me to procure larger grants from federal and non-federal agencies to conduct cutting-edge breast cancer research at Roswell Park. ”

– **Gokul Das, PhD**
Associate Professor
Department of Pharmacology & Therapeutics
Co-Director, RPCI Breast Disease Site Research Group
Roswell Park Cancer Institute





Anne Marie, Ross, Luca and Rosalie Comaratta during Ross' treatment at Roswell Park.

Overcoming Financial Barriers to Treatment

When certain kinds of leukemia or myeloma affect the bone marrow's or blood's ability to function, blood and marrow transplant (BMT) may be the patient's only hope. The first step toward BMT is HLA testing. HLA is a protein found on most of the cells in your body, and this testing determines whether a potential donor's HLA is compatible with the patient's.

The costs surrounding HLA testing — which include the search process, the potential donors' physicals, information sessions and more — can be prohibitive. While some insurance policies cover a portion or the whole cost, too many patients still have little or no coverage.

Anne Marie Comaratta knows this story from all sides. Her husband, Ross, did The Ride For Roswell for nine years in his commitment to raising funds to help cancer patients at Roswell Park. Then came the terrible day no one wants to imagine: Ross was diagnosed with acute myelogenous leukemia. Now he was a Roswell Park patient. Now he needed a bone marrow transplant.

A rider. A patient. A transplant recipient.

A banker who understood the full impact of the cost.

While the Comarattas' first instinct was to get Ross' seven siblings tested, his doctors advised against it because the exorbitant out-of-pocket cost would fall to Ross and Anne Marie.

So they tested four siblings, and Ross' brother Mark was a match. Unfortunately that transplant failed, and the Comarattas had to turn to the international Be the Match list for a new donor — incurring even more costs. Be the Match helps patients connect with volunteer donors around the world. "We were responsible for not only the initial search process, but all of the costs related to physicals and information sessions for our German donor," Anne Marie explains.



As a banker, Ross stressed over how to make it work. Between insurance coverage and digging into their savings, they were able to cover the costs of his HLA testing on their own. Anne Marie came away with the stark awareness that most families don't have the same fallbacks.

We at Roswell Park are happy to share that from now on, a portion of community donations to the Roswell Park Cancer Institute, including those to the Ride, will be dedicated to covering the cost of HLA testing for those whose insurance will not cover it.

Sadly, in 2016 Ross lost his battle after a short remission. Anne Marie, their two children and a team of devoted family and friends continue to Ride For Roswell in his memory as Team RossWell.

Anne Marie is glad that Roswell Park is now providing this extra support to families who need it. It will always be important to her.

"If a family like ours, with top-notch insurance and solid financial means, feels stress from the costs associated with HLA testing, how does it affect families in a tenuous financial spot? The thought of families having to take out loans to cover HLA testing costs breaks my heart."

Supporting HLA testing is just one more way Roswell Park strives to provide comprehensive care for its patients and their families.

"While I hope no one ever has to spend time at Roswell," Anne Marie says, "if you do, you come to understand that it is a hospital built on caring relationships. This is what we love best about Roswell Park."

"My husband would be so happy and proud to know that there is this effort. Covering HLA testing for these families will be game-changing and, God willing, life-changing."

— Anne Marie Comaratta



Support in Action: Giving a Second Chance

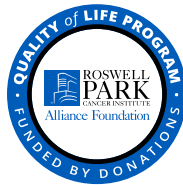
Catie underwent her second BMT while battling acute myelogenous leukemia last summer. She did not have a good match for her first transplant, but thanks to the generosity of Roswell Park donors she was able to undergo a second round of testing that identified three good matches.

"Since it was Catie's second transplant, the financial burden would have been very difficult," says her mom, Carolyn.

Sadly, after a courageous fight, Catie passed away in October. She was 16.

Carolyn is grateful to the donors who gave her daughter a fighting chance at a time when other treatment options were limited. "For families who are battling cancer, having one fewer thing to worry about can make an incredible difference."





Helping Patients Cope

Quality-of-Life Grants

When you or a loved one is fighting cancer, every bit of help and support makes life a little easier. It's important to us at Roswell Park to make every aspect of quality of life as good as possible for our patients and their loved ones. That's why the Roswell Park Alliance Foundation devotes a portion of donations each year to supporting quality-of-life grants around the Institute.

From arts & crafts to coffee carts to family support, these grants ensure that Roswell Park patients can focus on their fight while remembering that cancer doesn't define them.

For 2017-18, \$709,541 was distributed among 32 submissions. Here are some highlights.

Amazon Echo Dot

The Dot is a hands-free, voice-controlled speaker you can activate to make phone calls, play music, hear the news and more. Just call out "Alexa" and tell the device what you would like it to do next. Ten Dots have been purchased for the rooms of blood and marrow transplant (BMT) inpatients, whose hospital stays average 30 days.



"Alexa has been a big help and a wonderful distraction," says Roswell Park BMT patient Janice McCoy. "When I need to wake up, or want Alexa to tell me a story or joke or sing me a lullaby, all I have to do is ask. Alexa is wonderful company when family or staff aren't around. I'm thrilled that it's been provided to me during my stay."

Kara Eaton-Weaver, Executive Director of the Office of the Patient/Family Experience, applied for this grant. "The idea to purchase Amazon Echo Dots came out of a discussion with my staff on how best to treat the monotony of longer inpatient stays, and so far the feedback from the patients who've received the devices has been very positive."

A New Dryer for the Family Waiting Area on the Hospital's 5th Floor

The fifth floor cares for patients long term who have had leukemia, lymphoma or a bone marrow transplant. The majority of these patients come from out of town, and so do their caregivers. Having laundry services available in a convenient location in the hospital — free of charge — lifts a great burden.

Patients are often more comfortable wearing their own clothes than hospital-provided options. "A vast majority of our patients are not local, and their caregivers have limited amounts of resources. Being able to do laundry here alleviates stress on the caregiver and provides some semblance of normalcy for the patient's comfort," says 5 North RN Maureen Rogers, who saw the need for the new dryer and applied for the grant.

Sibling Mentor Program

The lives of children whose siblings have cancer can be greatly disrupted by the demands of their brother's or sister's cancer treatment. At the same time, they are experiencing some difficult emotions, and their parents are, naturally and unfortunately, less available to them. These children often start to express emotional and behavioral difficulties such as anxiety, depression and post-traumatic stress symptoms.

The Department of Pediatrics is launching a new program for siblings of cancer patients to help them understand and express the feelings resulting from their sibling's diagnosis and treatment. The program will also help them to become peer mentors for future groups.

At each of eight sessions, the innovative program will explore a particular emotion through sensory activities, with the goal of developing a deeper understanding of the children's emotions and helping them cope with them. A Roswell Park team composed of a psychologist, a pediatric medical psychiatrist and our integrative medicine program manager will run the program.

"We hope to give siblings a constructive and creative way to explore their emotions and offer them the support they need to move forward with their lives during a very confusing and frightening time — and in turn, be able to apply what they have learned to help other siblings successfully navigate the uncertainties of having a brother or sister with cancer," says Doug McDaniel, Program Manager, Integrative Medicine.



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



"Alexa has been a big help and a wonderful distraction."

— Janice, BMT patient

This year, donations allowed Roswell Park to launch and continue 32 quality-of-life programs for a total of \$709,541.

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marrow transplant. Stella says the Courage of Carly Fund has done so many things for her, she can't even list them all.

Most recently the Courage of Carly Fund provided a personal shopper to help her pick out a prom dress for Roswell Park's teen prom. "I felt like a princess after being all glammed up," she says. **"It's just amazing, all the things made possible by generous donors."**

With the support provided by generous donations from Roswell Park friends like you, the Courage of Carly Fund looks forward to a closer day when we can announce that we have eliminated cancer for good, and no child will ever have to fight this disease again.

Donations to the Courage of Carly Fund recently enabled Roswell Park to fund three pediatric research projects. Learn more at **CourageofCarlyFund.org**.



With help from the Courage of Carly Fund, Stella found the perfect dress to wear for the 2017 Roswell Park teen prom.