

Donor Dollars at Work

Summer 2017

Travels From Ohio

Hope in the Fight Against Ovarian Cancer



KayEllen remembers well the first time she met Dr. Kunle Odunsi.

"I was instantly aware of his compassion and comforted by it," she says, "and by his passion for what he does and his knowledge. I knew I was in good hands."

She had come to Roswell Park from her hometown in Ohio to see if she qualified for a clinical trial for an ovarian cancer vaccine run by Dr. Odunsi, Roswell Park's Deputy Director and Chair of Gynecologic Oncology. "I felt kind of like I was going to a job interview. But it was the interview of my life!"

She's now returned to Buffalo many times since that day in 2010 to see Dr. Odunsi and his team, having participated in a series of three clinical trials to find a vaccine against recurrence and making many other trips for follow-up appointments. And she's thrilled to say she's cancer-free.

But she also can't forget the day of her diagnosis.

It was her birthday in 2008, and she was stunned to hear she had stage 3 ovarian cancer. KayEllen immediately had surgery and began chemotherapy, which successfully eradicated the disease.

But knowing ovarian cancer's high recurrence rate, she and her family were not going to sit still. It was her daughter, Nicole, who learned about Roswell Park's clinical trials in the prevention of ovarian cancer recurrence. KayEllen now makes the trip from Ohio to Buffalo several times a year, usually with her

(continued on back page)



KayEllen Gebhart



Dr. Odunsi

What's Inside

- Travels From Ohio: Hope in the Fight Against Ovarian Cancer [p1](#)
- Quality-of-Life Programs at Roswell Park [p2-3](#)
- Twelve SAC-Greenlighted Research Projects [p4-7](#)



James Smaldino with patient and Boogie Board eWriter

Quality-of-Life Programs at Roswell Park

There are many phases in the battle against cancer. Patients often have specialized needs after surgery; after hospitalization; before, during and after chemotherapy; and more — all of them times when changes can be frustrating and even frightening.

For this reason Roswell Park is committed to providing patients with quality-of-life programs that give critical support in every stage of the fight in areas ranging from psychosocial to spiritual to diversionary. But the only way we are able to fund these programs is with your generous support.

Last summer, your donations provided \$700,000 to fund 29 quality-of-life programs selected by a committee of institute staff who evaluated them based on likely impact on patients. The programs were then rolled out to patients in the fall.

Here are a few of those programs, which give our patients

more control over their battle and take some weight off their shoulders as your gift allows Roswell Park to go the extra mile.

Boogie Board eWriters

For patients who have had surgery to remove their voice boxes, it can be frustrating trying to find a new way to communicate. James Smaldino, Roswell Park Supervising Speech Language Pathologist in Head and Neck Surgery, learned about Boogie Board eWriters from some of his patients.

“They said they loved them,” he says. “So I wanted to get them in the hands of more people.”

Patients write on the board with a stylus and erase it with the touch of a button. The boards are compact and easy to carry.



Smaldino was very happy to get the quality-of-life grant for their purchase. He notes that patients might not be able to afford the eWriters on their own, and insurance won't cover them. Thanks to the generous support of donors and Upstate Pharmacy Ltd., the Boogie Boards are available to everyone who needs one and are theirs to keep.

He adds: "For somebody who has lost their ability to communicate verbally, whether it's through surgery or having a long-term breathing tube in place, it really gives them an opportunity to communicate what they're feeling, questions for the medical staff regarding their condition and prognosis, etc. It puts a little bit more control back in their hands immediately when they can ask their own questions."

Chemotherapy Orientation Bags

Megan Battaglia kept hearing about the things Roswell Park's chemotherapy patients wished they'd known before starting their treatment. So the Senior Patient Education Facilitator and her team in the Roswell Park Resource Center designed a gift for every new chemo patient: a chemotherapy orientation bag.

Battaglia says she and her staff had wanted to begin this program for a long time. But it's only because of the donor support they received from the quality-of-life grant that they were able to make it a reality. "Donors providing the money for us to put these kits together allowed us to start the program. We couldn't have done it without the funding from the Alliance Foundation.

"It's a wonderful gift that should make patients' chemo appointments more comfortable and help them make sure they have all the things they need for their day," she says. The bags contain helpful items ranging from a water bottle to information on handling side effects to a coloring book that helps adult patients pass the time.

Possibly the most important outcome, Battaglia says, is the chance to talk one on one with each patient and do a personal orientation during this visit, making sure they fully understand the process and know where to go when they have questions.

The chemo orientation bags are distributed by patient education staff in the chemo infusion clinic, or patients can pick up their orientation bag in the Resource Center on the first floor of Roswell Park's main building.

"One patient told me: 'Everyone here just seems to go out of their way to make me feel comfortable and to make everything easier. This bag is such a pretty thing. I can't believe I'm on my way to chemo and I'm smiling.'"

LegalCare at Roswell Park

When you're fighting cancer, that fight is the only thing you should have to worry about. Your job, your insurance, will preparation — issues like these should never add to a patient's burden. But sometimes these concerns do become reality, and we know that this kind of stress can impede recovery. That's where LegalCare at Roswell Park comes in.


LegalCare is a partnership between Roswell Park and the University at Buffalo School of Law in which certified, supervised student-attorneys provide assistance on health-related legal needs to patients who otherwise could not afford it. Your giving to Roswell Park enabled a quality-of-life grant contributing to LegalCare's funding so it could continue working to improve outcomes for patients in all aspects of their lives.

"Legal needs that you might experience over the course of a lifetime tend to happen a lot faster when you have cancer," says Danielle Pelfrey Duryea, LegalCare Legal Director and UB Law Clinical Professor. They also often follow a predictable pattern, such as insurance issues in the diagnosis stage; employment in the treatment stage; debt and family law after recovery. The team works to catch problems upstream and prevent any need to go to court.

"We so often have people tell us 'I was really worried about this — now I can just cross it off my list and focus on what's really important.' That is so rewarding."



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



Roswell Park is world-renowned as a place of innovation, research and exceptional care. But not everyone knows the critical role donor funding plays in making each one of these a reality.

Because of special research grants your support enables, our doctors and scientists are able to take innovative ideas and get them well off the ground. Our Scientific Advisory Committee plays a role in some of these awards, selecting proposals by Roswell Park researchers who apply and compete for grant funding; others are selected through a separate but also rigorous process. In every instance, projects are carefully reviewed for their ability to find cancer cures and save lives, ensuring that your gifts are used only for the most promising projects.

This spring, 12 research projects were given the green light and a total of \$702,918 to get started.

The results this seed funding enables frequently lead to national, long-term funding and help turn ideas into real treatment. Our scientists discuss their exploration on the following pages.

12 research projects greenlighted by our Scientific Advisory Committee



Bladder Cancer

Improving tumor detection to increase success in treating bladder cancer

"Bladder cancer is the fourth most common cancer in men and the eighth most common in women. It has a high rate of recurrence, possibly because of poor detection after the first treatment is completed. We will explore whether improved tumor detection using multifunctional agents for image-guided photodynamic therapy could lead to a higher rate of success in treating bladder cancer when combined with other treatment methods."

Prostate Cancer

Transforming cancer stem cells to decrease prostate cancer recurrence risk

"Androgen deprivation therapy (ADT) is the standard of care for advanced prostate cancer. While initial response to ADT is good, recurrence is frequent, indicating that a common cell must survive and trigger the recurrence. Cancer stem cells are the likely survivor and trigger, so our project will investigate whether differentiation therapy against cancer stem cells – in which they are transformed into a different kind of cell – could decrease the risk of recurrence, thereby improving quality of life and saving more lives."

Mindfulness and Breast Cancer

Managing treatment-related symptoms through mindfulness-based intervention

"With the advancement of targeted therapies for breast cancer, survival for women diagnosed with metastatic disease has improved and will continue to trend upward. Many of these survivors suffer treatment-related symptoms like pain, fatigue or anxiety. Our goal is to provide effective interventions for these symptoms. This study will develop a mindfulness-based intervention geared toward the specific needs of these patients to manage their symptoms and improve their quality of life."

Sepsis

Combating septic inflammation in immune-compromised patients

"Sepsis is a major cause of mortality in cancer patients, being fatal in 28 to 50 percent of cases. When not fatal, it frequently leaves survivors with permanent organ damage. The danger is particularly urgent because cancer patients are often immune-compromised and must endure treatments making them more susceptible to infections. Our laboratory has shown a secreted factor in the blood known as ST6Gal-1 to be effective in combating septic inflammation, and with the help of this funding we will complete the evaluation of its use as a potential intervention to prevent organ damage and save lives."



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Breast Cancer

Repurposing tamoxifen to treat triple negative breast cancers

"Triple negative breast cancers (TNBC), the most aggressive and difficult to treat form of breast cancer, represent about 15 percent of all breast cancer diagnoses in the U.S. and pose a great challenge in treatment. Therapies that are successful in other hormone-related cancers fail here, and while chemotherapy is effective in the beginning, it fails to stop progression. To meet the urgent need to identify new targets and develop new therapeutic studies for this disease, we propose repurposing the estrogen-blocking breast cancer drug tamoxifen to treat a different type of breast cancer (TNBC), with the intent to move on to clinical trials at a rapid pace."

Prevention

Developing successful cancer prevention programs for the Puerto Rican community of Western New York

"The goal of our study is to define the cancer prevention and early detection health education needs and concerns of the underserved Puerto Rican community in Western New York. This will include the use of social media and internet technologies to inform, develop and aid in the implementation and dissemination of relevant cancer-related education, services, interventions and research opportunities using communication platforms preferred by this community. From the results of this initial study, we expect to identify opportunities for developing cancer prevention programs for this demographic and continue with a larger study to deliver and evaluate relevant strategies."

Childhood Acute Lymphoblastic Leukemia

Identifying genetic determinants of treatment-related toxicities and outcomes

"In a trial of treatment of childhood acute lymphoblastic leukemia, it was found that, compared with children of European ancestry, Hispanic children have lower rates of therapy-related bone tissue death and fracture but higher rates of relapse and a greater number of complications. In this study we hope to determine whether genetic ancestry could be responsible for these disparities and will also perform a genome-wide analysis to pinpoint the genetic determinants of treatment-related toxicities and outcomes, ultimately enabling us to develop a larger grant to evaluate potential clinical applications."

Pediatric Rhabdomyosarcoma

Improving the survival rate of pediatric patients with aRMS through a new therapeutic intervention

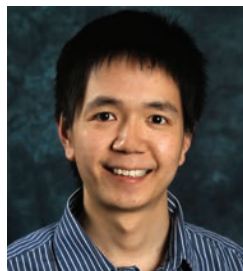
"Pediatric patients with alveolar rhabdomyosarcoma (aRMS) – an aggressive soft-tissue malignancy of the skeletal muscle – have a five-year survival rate of less than 50 percent. The tumors of this disease express a high level of oncoprotein that promotes tumor cell growth, migration and metastasis. This SAC funding enables us to explore the ability of a potential therapeutic agent to negate the biological actions of this oncoprotein that may offer new opportunity for therapeutic intervention in aRMS."



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Psychosocial Support

Exploring how perceptions of time affect healthy and unhealthy behaviors in cancer survivors

"Our project will focus on helping cancer survivors stay healthy. Some cancer survivors naturally experience a shift to valuing the present over the future, making it difficult to see the value in healthy behaviors such as eliminating tobacco use or increasing physical activity. We will examine how perceptions of the present and future are related to health behaviors among cancer survivors. The findings will help to identify those likely to struggle staying healthy, identify new therapeutic targets to engage cancer survivors in healthy behaviors, and develop therapeutic interventions to increase healthy behaviors."

Ovarian Cancer

Identifying gene mutations to improve screening methods for familial ovarian cancer

"We have developed evidence that a particular ovarian cancer gene passed down to a woman from her paternal grandmother is linked to increased cancer risk in that woman and an earlier age of onset. So, if your father's mother had ovarian cancer, your chance of developing it is higher than if your mother's mother had had it. This tells us that the gene is likely to be on the X chromosome. If so, men will always pass this gene to their daughters, and we will need to develop screening strategies and education for fathers and brothers. This funding will support studies to identify the gene and its mutations that are likely to cause disease, and to understand how to screen families in the future."

Colorectal Cancer

Investigating the significance of a specific biomarker on colorectal cancer survival

"Colorectal cancer is a major common human cancer making up about 9 percent of all cancer types in the U.S. We propose to investigate whether a specific biomarker is important in colorectal cancer survival as well as whether our recently developed novel anticancer drug, called FL118, can use that biomarker for future colorectal cancer patient selection for FL118-personalized medicine and targeted clinical trials. This funding will also support oral tests to determine whether oral administration of FL118 is the best way for patients."

Skin Cancer

Improving the efficacy of existing therapy agents

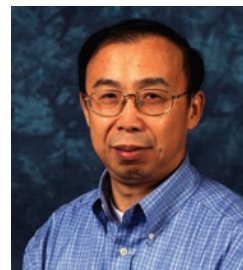
"Skin cancers are the most common human cancers and are primarily induced by ultraviolet radiation. Ultraviolet radiation can directly damage cellular DNA, but it also induces secondary changes in the cells that lead to DNA damage, mutations and cancer formation. We uncovered a novel regulator of this secondary cell damage process. Our work focuses on uncovering how this regulator increases cell damage and how modifying the activity of this regulator can be used to make existing cancer therapy agents more targeted and more efficacious."



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husband or daughter. “We call them vacations with needles,” she says. “We could write a travel book about what you can do in Buffalo when you’re waiting to go back to the clinic the next day!”

It’s only possible because of donors like you.

When KayEllen learned that donations are enabling Roswell Park to advance these studies, she was grateful to the donors for giving hope to other patients like her.

“Their gifts are going to change and maybe save someone’s life,” she says. “And specifically through clinical trials. That’s how we’re developing these new treatments. If it weren’t for donors, we wouldn’t be having them.”

And we’re not done yet. New funding is still needed to continue pushing these studies forward and make a vaccine readily available. Recurrence rates of ovarian cancer are high in its later stages, and women diagnosed at stages 3 and 4 face low survival rates. That’s why Dr. Odunsi and his team are concentrating on a series of vaccine therapies that use the immune system itself to fight ovarian cancer.

While a large part of his project is funded by a prestigious award from the National Cancer Institute, critical additional funding is still needed from Roswell Park.

Your continued support allows Roswell Park to meet this need, and because of you, Dr. Odunsi and his team are able to continue their work to effectively reduce the rate of ovarian cancer recurrence.

A doctor like this makes all the difference.

KayEllen can’t say enough about her favorite doctor. “Dr. Odunsi always makes you feel like he has time just for you when you know he has hundreds of patients. But he gives you that feeling that when you are sitting across from him, you are his only patient. His life is his work. We just couldn’t say enough about Dr. Odunsi and Roswell. We have such confidence in everything.”

And she feels great now. She’s been participating in the clinical trials for seven years and has had no recurrences. She and her husband — her college sweetheart — just celebrated their 40th anniversary. She walks three, four, even six miles a day. She teaches, runs her dog-walking business of 20 years, spends time with her grandson, sews pillowcases for kids with cancer, and plans her next trips to see Dr. Odunsi at Roswell Park.

“Cancer is somber,” she says, “but life shouldn’t be. We just have to do the best we can.”