

2015 Volume II

Dialogue

Wilmot Cancer Institute | University of Rochester Medical Center

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MEDICINE

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Letter from the Director



Jonathan W. Friedberg, M.D., M.M.Sc.
Director, Wilmot Cancer Institute

Hello friends of the Wilmot Cancer Institute,

Research drives advances in cancer treatment, and the discoveries of recent decades have brought us to a new era in oncology. Our growing understanding of biology is providing physicians and researchers more avenues to explore the prevention and treatment of cancer.

Over the course of my career as a clinical investigator, I have witnessed an evolution in clinical trial development. Clinical trials adhere to strict protocols to ensure the safety of participants, and they are designed to evaluate effectiveness, dose and outcomes of a novel treatment strategy in a systematic way. Historically, that meant slow, incremental progress. Today, new technology and innovative study designs utilize our knowledge of specific cancer abnormalities, dramatically speeding up the drug development process. Even in a phase 1 study, we may see participants respond to experimental therapies and derive immediate and significant benefit from participation in these trials, as described in this issue of *Dialogue*.

As chair of the Lymphoma Committee for a national cooperative cancer research group called SWOG, I help oversee the agenda of National Cancer Institute-sponsored clinical research, and I'm happy to report that, without question, Wilmot Cancer Institute is at the forefront.

We have long offered clinical trials that have brought new therapies to patients years before they were widely available, and expanding our clinical trial infrastructure in Rochester and the Finger Lakes region is one of my key goals. We have more than 100 clinical trials actively enrolling patients, and our portfolio of local and national trials sets us apart from all other cancer care providers in upstate New York. Our physicians are members and leaders of national research trials, including precision medicine studies. Our scientists and physicians also collaborate to translate findings from laboratories here in Rochester into novel treatment strategies.

Participation in these trials can truly transform the lives of our patients. I'm so grateful for those who volunteer to participate in clinical trials and for the large team of faculty and staff involved in conducting these studies. Together, we have formed a vibrant partnership which is improving cancer care today and making us a national destination for clinical expertise and access to novel therapies.



Jonathan W. Friedberg, M.D., M.M.Sc.

On the Cover

Pancreatic cancer survivor Walt Standhart of Greece, N.Y., is among the grateful clinical trial participants at Wilmot Cancer Institute. Diagnosed in 2012, Standhart recently returned to competitive running.

cover photo: Matt Wittmeyer

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COVER STORY

THE PACE OF PROGRESS

Clinical trials are evolving to bring new therapies to patients more quickly. For Walt Standhart, who had pancreatic

cancer, they presented an additional treatment option and the opportunity to advance science.



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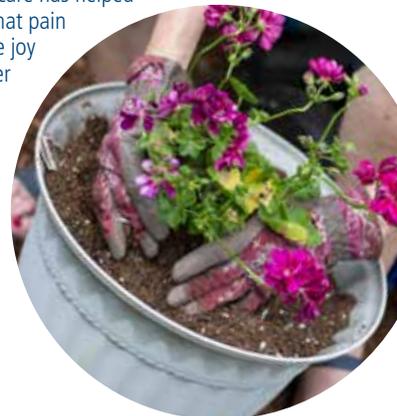
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More than medicine

Multiple myeloma made debilitating pain part of Rosemary Grandusky's life. Palliative care has helped her manage that pain and regain the joy she finds in her gardens and her grandchildren.



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Wilmot Cancer Institute is collaborating to bring a new cancer center to the Finger Lakes and Southern Tier region.

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Committed to breast cancer research

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Wilmot scientist joins elite group of international award winners

Lynne Maquat, Ph.D., who studies RNA biology, won the 2015 Gairdner International Award, Canada's major science prize given to five biomedical researchers around the world in celebration of revolutionary ideas and discoveries. Since the award's inception in 1959, approximately one in four Gairdner winners have gone on to receive the Nobel Prize.

Maquat discovered a cellular quality-control mechanism that derails the production of unwanted proteins in the body that can disrupt normal processes and initiate disease. In the context of cancer, she is investigating how to make



chemotherapy more effective by stopping the quality-control mechanism. Although much more study is needed, her work is providing insights into treatment strategies for future cancer patients. Her chemotherapy-related research was recently published in the journal *Nature Communications*.

An Edelman-Gardner seed grant through the Wilmot Cancer Institute supported her lab's cancer studies.

Maquat holds the J. Lowell Orbison Endowed Chair and is a Professor of Biochemistry and Biophysics at the University of Rochester Medical Center. In 2011, she was elected to the National Academy of Sciences.

Wilmot Cancer Institute re-certified by national quality improvement program



Initiative (QOPI) Certification Program, an affiliate of the American Society of Clinical Oncology (ASCO). The QOPI Certification Program (QCP) provides a three-year certification for outpatient hematology-oncology practices that meet nationally recognized standards for quality cancer care.

UR Medicine's Wilmot Cancer Institute has received reaccreditation by the Quality Oncology Practice

Wilmot Cancer Institute is the only QOPI-certified cancer care provider in the Rochester and Finger Lakes region. The QOPI certification applies to all Wilmot Cancer Institute sites that offer hematology and oncology services, including Geneva, Highland Hospital, Park Ridge, Pluta Cancer Center, Sands Cancer Center, Strong West and the James P. Wilmot Cancer Center at Strong Memorial Hospital. UR Medicine's Division of Hematology/Oncology, based at Wilmot Cancer Center, initially achieved this certification in June 2012.

The QCP is a project of ASCO's Institute for Quality, an ASCO affiliate dedicated to innovative quality improvement programs. For more information, please visit <http://qopi.asco.org/certification.html>.

Pathologist selected for local grant to study bone metastasis

The Breast Cancer Coalition of Rochester selected Zhenqiang Yao, B. Med., research assistant professor in the Department of Pathology and Laboratory Medicine, to receive its 2015 Research Award. Yao, who is studying an "all-in-one" agent to be used when breast cancer spreads to the bone, received \$50,000 from the Coalition, which has been funding area researchers since 2003.

Yao is investigating whether a particular protein inhibitor can kill cancer cells while simultaneously preventing bone breakdown and stimulating bone growth. Most breast cancer deaths occur when the disease spreads to other parts of the body.



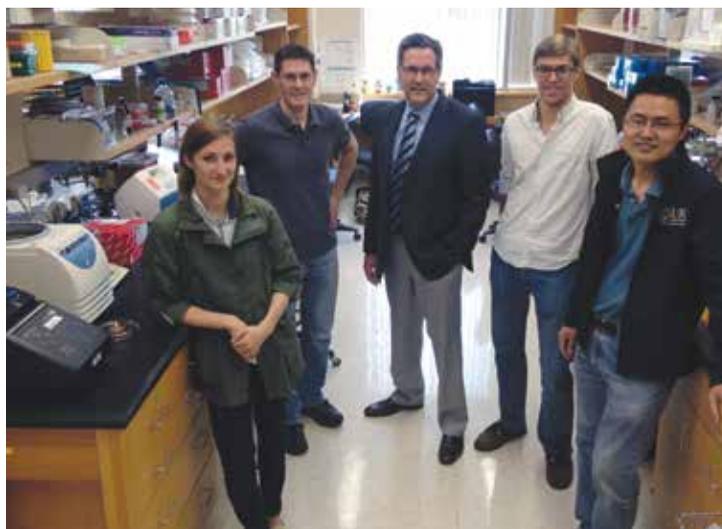
Chief surgeon wins grant to continue pancreatic cancer studies

The Pancreatic Cancer Action Network recently awarded \$300,000 to support the research of David C. Linehan, M.D., chair of the UR Department of Surgery and director of Clinical Operations at Wilmot. Linehan is investigating an experimental treatment and its appropriate dose and timing in mice, so that future clinical trials can be designed to benefit cancer patients.



Linehan's research focuses on cells known as inflammatory monocytes (IMs), which are non-tumor cells produced in the bone marrow that migrate toward pancreas tumors and promote the spread of the disease. In earlier mouse studies, he showed that by blocking IMs with a novel small-molecule inhibitor, he could slow tumor growth and prevent metastasis. He then completed a phase 1b clinical trial for patients with locally advanced disease, evaluating an experimental IM inhibitor in combination with standard chemotherapy.

Although the drug was well tolerated and showed promise for controlling localized disease, it is unclear whether the same approach will work for patients with cancer that has already spread. The new mouse studies will help to clarify which subgroups



David C. Linehan, M.D., in his laboratory with his research team.

of patients would benefit the most, as well as the appropriate doses and combinations with other therapies.

Survival of pancreatic cancer has not improved much in 40 years. At diagnosis, about half of all patients have disease that has already spread, mostly to the liver. Therefore, Linehan says, targeting metastasis is a key to boosting survival. The funding cycle for the award began July 1.

Blood and Marrow Transplant Program earns another stamp of excellence



The Blood and Marrow Transplant Program's leadership team includes Michael W. Becker, M.D., left, Margaret Blaney, R.N.; Laurie Milner, M.D.; Jane Liesveld, M.D., and Sue Frauenhofer.

The Blood and Marrow Transplant (BMT) Program at Wilmot Cancer Institute was recognized for its high level of care and detailed quality management processes with a three-year re-accreditation from the Foundation for the Accreditation of Cellular Therapy (FACT).

Wilmot's BMT program was accredited for all types of adult and pediatric blood and marrow transplantation, as well as collection and processing procedures. Continuously accredited since 2000, Wilmot's BMT Program performs 130 to 140 transplants annually for conditions such as leukemia, lymphoma and non-cancerous hematologic conditions including sickle cell anemia and aplastic anemia. It is one of the largest FACT-accredited programs in New York state.

FACT is the only accrediting organization that addresses all aspects of cellular therapy treatments, including collection, processing and administration. Its accreditation is recognized by several external organizations, including government agencies and insurance companies, as a symbol for excellence in cellular therapy.



Wes and Alyssa Jones, at home in Rochester.

Clinical trials: The root of progress, the future of excellent cancer care

By Leslie Orr

Wes Jones was running out of time against a rare type of lymphoma. The cancer was outpacing eight separate attempts to treat the disease, evident from the softball-sized tumor growing rapidly across his right shoulder and metastasis to his central nervous system. During his darkest days, Jones, who was 34, got his affairs in order and moved up the date to marry his fiancée, Alyssa Sanko.

His oncologist, Paul Barr, however had one last idea—a Hail Mary pass in the form of a phase 1 clinical trial.

The results were so stunning that Jones' story is legendary at UR Medicine's Wilmot Cancer Institute. Within three days of taking the experimental therapy in the spring of 2011, his tumors shrank, and in eight weeks, they were nearly gone. In 13 weeks, he was healthy enough to endure a stem-cell transplant, and this summer, Wes Jones remains in complete remission.

"The clinical trial saved my life," says Jones, now 39, a Brighton resident, and human resources director for a Virginia-based company. "Nothing else was working. So, without that trial, I probably wouldn't be here today."

Cancer is a complex set of diseases, and clinical trials play a major role in helping scientists methodically gather the evidence to introduce new treatments. A major strength of the Wilmot Cancer Institute is its leadership role in the Finger Lakes region for providing patients access to a local and national portfolio of trials. Just since 2008, Wilmot has seen its clinical trial enrollment soar 128 percent.

And as clinical studies evolve—for example, grouping patients in new ways to provide benefits more quickly—it's important to have knowledgeable faculty like Barr to serve as head of Wilmot's Clinical Trials Office. Not only has Barr designed and supervised several lymphoma trials himself, he is plugged into what colleagues at other institutions are doing.

“We’re not settling for great care based on today’s treatments. We want to lead the way to the next generation of therapies.”

– Jonathan W. Friedberg, M.D., M.M.Sc.

To celebrate his remission, Wes and Alyssa Jones renewed their wedding vows in 2012. The couple also hosted a joyful reception, where Paul Barr, M.D., was among the honored guests.



Paul Barr, M.D.



The value of clinical trials

As Jones grew sicker, Barr paved the way for him to enroll in a clinical study at the Dana-Farber Cancer Institute in Boston.

Later, Barr and his Dana-Farber collaborators would describe Jones' remarkable story for fellow oncologists across the country in a case report for the *Journal of the National Comprehensive Cancer Network*.

"This is one of my favorite cases of all time," Barr says. "Not only did Wes experience a great result, but his case perfectly illustrates the value of clinical trials and the way they have changed in recent years."

Increasingly, clinical studies are being organized to look at the molecular characteristics of tumors and discover whether newer or repurposed drugs can block mutations in cancer genes. Older trials tended to focus on the organ in which the

disease started and were designed to look for small differences between two treatments. The evolving approach allows patients with a genetic mutation that might respond to treatment to enroll immediately in an early-phase study that could benefit them.

For example, Jones received the drug crizotinib, which was originally approved by the Food and Drug Administration to treat non-small cell lung cancer. But crizotinib also is known to act on the ALK1 protein pathway, which is involved in anaplastic large cell lymphoma, the type of blood cancer that plagued Jones. Because the ALK1 mutation was the common link between lung cancer and lymphoma, Jones was able to receive crizotinib through the Boston research group. He still takes it as a maintenance drug.

Not all patients will have such a positive experience. And not all patients choose to participate in studies due to other health

problems, geography or the burdens of additional testing and hospital visits often required by clinical research. Still, clinical studies are at the root of scientific progress, Barr says, and they continue to be essential for the development of new and improved treatments using modern technology.

Jonathan W. Friedberg, M.D., M.M.Sc., director of the Wilmot Cancer Institute, emphasizes that perhaps the most important mission for cancer care in the years ahead is to improve patient access and understanding of clinical research.

"We're not settling for great care based on today's treatments," Friedberg says. "We want to lead the way to the next generation of therapies."

Friedberg, for example, and Patrick Reagan, M.D., are working with the National Cancer Institute to bring a progressive immunotherapy known as CAR T-cell technology to the Rochester region. Currently, the only places offering CAR T-cell therapy in the northeastern U.S. aside from the NCI are Memorial Sloan Kettering in New York City and the University of Pennsylvania in Philadelphia.

CAR T-cell therapy involves extracting a patient's healthy immune cells (T-cells) from the blood, then genetically engineering them and expanding them outside the body so they will identify proteins on the surface of cancer cells. When the T-cells are reintroduced into the patient's bloodstream, they are designed to seek and destroy cancer.

"It's very exciting, futuristic technology," Friedberg says. "Not all patients respond and sometimes people have a disease for which none of the treatments will be effective. But after standard care is exhausted, studies like these are often less toxic than conventional therapies and they allow us to watch for responses very closely. And some patients do very well."



Wilmot is involved in other important national clinical research initiatives:

- This spring, the NCI launched a revolutionary new study called Molecular Analysis for Therapy Choice, or MATCH. It is known as a “basket” trial. More than 3,000 people nationwide with different types of advanced solid tumors and lymphomas will be enrolled. All patients will undergo DNA sequencing. There are no control groups, and therefore everyone enrolled, with an eligible mutation, will have an opportunity to receive a new drug. Researchers will look for hundreds of mutations that exist among the enrolled patients, and then match them to drugs that are already FDA-approved as treatments for other cancers or illnesses. Wilmot oncologist Marcus Noel, M.D., is designing an arm of the study, hence a “basket,” that would match patients with the non-V600 BRAF mutation to Mekinist, a drug typically used to treat advanced melanoma. The FDA has sanctioned the MATCH study, and could approve drugs based on data from that trial alone.
- Lung-MAP, also known as Lung Cancer Master Protocol, is being led in the Finger Lakes region by Wilmot oncologist Eric Kim, M.D. This study was specially designed to allow doctors to test a handful of experimental treatments at the same time, based on a tumor’s molecular profile. Lung-MAP patients are placed into the groups that are most likely to benefit them, depending upon

their genetic tumor type. Not only does it provide a more personalized option, but the trial was also designed to address an unmet need for new therapies for squamous cell carcinoma, a lung cancer subtype associated with smoking and fewer breakthroughs.

- The Cancer Control & Survivorship research team at Wilmot is the leader in a nationwide network investigating therapies for cancer-related side effects such as fatigue, nausea, and cognitive impairment known as “chemo-brain.” The NCI designated Wilmot as a research hub for these types of studies, and awarded an \$18 million, five-year grant to support that role.

“This is the future of oncology,” Friedberg says. “People are watching these new, large trial networks very closely because if we’re able to spin out effective drugs faster, that will be an incredible opportunity for patients and for the entire cancer field.”

Wilmot has about 100 other cancer studies open for enrollment, plus 30 in the planning stages, another 30 that are no longer accruing patients but still have people on active treatment and 19 studies with patients in post-treatment follow-up. Additional cancer studies are open at the UR Medical Center through the departments of Urology (17 trials accruing bladder or prostate cancer patients), Radiation Oncology (approximately 30 open studies), and about 20 more cancer-related clinical studies through Surgery and Neurology. Many trials are open to patients at Wilmot’s

satellite sites. In total, several hundred patients are study participants.

The research is as varied as cancer itself. Some studies are very low risk, such as testing the effectiveness of a decision-making tool for patients with early-stage prostate cancer, or evaluating a new mouth rinse for oral infections from head and neck cancers. Others test immune therapies, vaccines, medical devices, or chemical agents designed to target malignancies in new ways.

The field of clinical research is moving fairly quickly, Barr notes. Wilmot is on track to strategically design homegrown studies in the near future.

For example, one such trial could convert a discovery from the laboratory of Mark Noble, Ph.D., to a clinical study for patients with recurrent glioblastoma, a type of brain cancer. Nimish Mohile, M.D., is working with Noble to design a phase 1 study to evaluate whether the widely used breast cancer drug tamoxifen, coupled with a second therapeutic agent identified by Noble’s team, can control this deadly malignancy. Earlier research suggests that tamoxifen has additional properties that might apply to other cancers including brain tumors. Noble’s laboratory is working on how to harness these other properties as a viable brain cancer treatment.

“This is exactly the purpose of bench science—to not only answer important scientific questions but to take the knowledge one step further, to benefit our patients,” says Hartmut “Hucky” Land, Ph.D., director of research at Wilmot.

“This is exactly the purpose of bench science—to not only answer important scientific questions but to take the knowledge one step further, to benefit our patients.” – Hartmut “Hucky” Land, Ph.D.



Walt Standhart runs on the Erie Canal path in Greece, and often wears a shirt embroidered with his thanks. He credits his current good health to a clinical study drug, along with outstanding care by surgeon Luke Schoeniger, M.D., Ph.D., and oncologist Mohamedtaki Tejani, M.D.

Helping to advance science

Pancreatic cancer survivor Walt Standhart, 70, is among the grateful clinical trial participants at Wilmot. He enrolled through the Department of Radiation Oncology following his cancer diagnosis in December of 2012. After successful surgery, Standhart was randomly assigned to a group that would receive standard chemotherapy plus the drug Tarceva, which was originally developed for advanced lung cancer but has been used to treat other types of cancer.

“Given the opportunity to get an additional therapy—even with uncertain benefits—I figured that I’m already into this and why not? And if it’s helpful to advance science, I was happy to do it,” Standhart says.

A marathon runner before the diagnosis, he was able to ease back onto the trails, first by walking his dog, then jogging and finally running again.

By 2014, Standhart was strong enough to compete in the Rochester Marathon. He also ran several other shorter races, qualifying him for a gold patch marking 200 miles of racing from the Greater Rochester Track Club. Standhart chalks up his good fortune to a variety of factors, including exercise and the clinical trial.

“Patients should be asking their oncologists about clinical trial options when they get a cancer diagnosis and then every time they discuss a new therapy,” Barr says. “Our goal is to make sure every patient has the opportunity to enroll if they wish.” 

CLINICAL TRIALS 101

Clinical trials stem from a need to identify better therapies to treat cancer and its side effects. Because it would be unethical to give new and potentially toxic treatments to patients and simply hope for the best, clinical trials serve as a coordinated, responsible and systematic way to evaluate safety, effectiveness, dose and outcomes. Institutional protocols and federal regulations are in place to protect patients, to make sure they understand the objectives of a study, and to help patients realistically plan for all possible outcomes, including death. The Research Subjects Review Board at the University of Rochester reviews and oversees all clinical trials to protect the rights and welfare of all study participants. Trials take place in steps:

PHASE 1 trials typically evaluate a new treatment in a small number of patients for safety and dose range. However, many new phase 1 studies are being designed with new enrollment criteria based on the molecular characteristics of a patient's tumor instead of age, disease stage or prior treatments. Early-phase trials are taking on greater importance, as they include more precise subsets of patients who might benefit from targeted therapies.

PHASE 2 trials also evaluate safety and effectiveness, and often recruit a larger number of patients.

PHASE 3 trials are usually designed to confirm a treatment's effectiveness and to compare it with standard care. The FDA often approves drugs based on data from phase 3 trials, although that method is changing, too.

THEN AND NOW

Older trials were often less efficient. For example, oncologists looking for a particular genomic link between a subtype of cancer and a targeted therapy would first have to screen the DNA of dozens or hundreds of patients to find just a couple of potential matches. Modern genomic technology speeds up that process because it allows scientists to hunt for many gene mutations at once.

As treatments improve, fewer trials require the use of a placebo (a sugar pill). Placebo-controlled trials are still important because they provide valuable information about side effects of treatment. But they often have cross-over options so that patients who receive the placebo eventually can receive the experimental therapy.

However, the vast majority of cancer-related studies today do not use a placebo. Instead, they compare the best standard treatments with standard treatment plus a new drug, or they enable patients with few options left to enroll and receive the latest experimental therapies.

COSTS

Most patients don't incur additional costs to participate in clinical trials. The study provides the therapy, and the oncologist bills insurance for office visits, blood tests and other standard forms of care.

Amy Rovitelli, senior regulatory coordinator, left, with senior health project coordinators Robin Boerman and Erin Cebula help lead Wilmot's Clinical Trials Office.





Rosemary Grandusky in her garden in Webster.



More than medicine: Palliative care helps restore comfort, control, for patients undergoing cancer treatment

By Lydia Fernandez

Rosemary Grandusky of Webster is used to being in control. She raised three children. She led surgical nursing teams at Genesee and Highland hospitals. She later helped to build a consulting business that brought in \$15 million in annual revenue.

But her multiple myeloma, diagnosed in 2007, changed that. This chronic form of blood cancer brought severe bone pain, multiple fractures and debilitating neuropathy. After two stem cell transplants, Grandusky remains on chemotherapy and has struggled with managing her pain.

Pain medications left her feeling so drugged and groggy that she couldn't drive or focus to do the things she wanted. When she took those medications, her kids would say she'd be in Never-Never Land, and they began to worry that she was depressed.

"I wasn't myself," she recalls. "With the drugs, they were in control. I was sleeping all the time. It took the fun out of living."

As a nurse, Grandusky knew there had to be something better, something that would allow her once again to sew and quilt, to garden and play with her grandchildren. She turned to UR Medicine's Palliative Care Program and connected with Cheryl Williams, M.D., who sees patients at Wilmot Cancer Institute's Pluta Cancer Center, Sands Cancer Center and Wilmot Cancer Institute in Geneva.

Together, they found a combination of strategies—including changing the type and timing of medication and only using narcotics for when the pain is disabling—that have allowed Grandusky to be herself again.

Cheryl Williams, M.D.



"I have a regimen I can follow and options I can choose from. This gives me the freedom to do the things I want," says Grandusky, who recently toured France even though her lower leg was fractured.

The palliative care approach

Sometimes confused with hospice, palliative care focuses on alleviating the pain and symptoms—such as nausea and shortness of breath—that can come with a serious illness like cancer and its treatment. But unlike hospice, it can accompany any and all desired medical treatment of one's cancer or other conditions. It's about helping patients and their families to live better while they're undergoing treatment.

For patients at Wilmot Cancer Institute, palliative care is an option right from diagnosis. Access to these services has now expanded to Wilmot's outpatient clinics throughout the Rochester and Finger Lakes region. These regional outpatient services are the first of their kind locally, and they complement the palliative services that have been available to patients during stays at UR Medicine's Strong Memorial Hospital, Highland Hospital and Thompson Hospital. In addition, the outpatient palliative care clinic at Wilmot Cancer Center expanded this summer to accommodate consultations five days a week.

"Palliative care is an integral part of providing high-quality cancer care," says Timothy E. Quill, M.D., director of UR Medicine's Palliative Care Program. "By getting involved earlier with patients, we can provide better care. If patients feel better, they will do better and have better outcomes."

By addressing pain and other symptoms, palliative care can allow patients to spend less time in the hospital and prevent emergency department visits. It can help them tolerate treatments longer, and an increasing body of research is showing that

Timothy E. Quill, M.D.



palliative care is helping people live longer. Palliative care physicians approach physical symptoms such as pain much like any other physician would, but they have had special training and have special expertise in these areas that can supplement usual treatments offered by non-palliative care specialists and generalist physicians. What also sets palliative care clinicians apart is their focus on the patient's goals around addressing those symptoms.

"It's about who you are and what's important to you foremost," Williams says. "Just because we have the technology doesn't mean it will fit your lifestyle and goals."

Grandusky's goals, for example, were less pain and a clear mind. She was willing to accept living with some pain in order to continue activities she loves and to spend quality time with her family and friends.

In order to understand a patient's goals, palliative care providers invest a lot of time listening. They provide a forum where patients and families can discuss how they feel, what worries them and what they want to do next. Very often, palliative care clinicians are as much mediators, facilitators and counselors as they are physicians.

Initial appointments can last an hour, and follow-up appointments can be just as long. The discussions include a wide range of emotional, social, practical and spiritual issues that arise with a cancer diagnosis and treatment.

"We try to see what patients and families are in need of and tailor our conversation accordingly," Quill says.

Focusing on the whole person

For Bob Walsh of Canandaigua, one of those needs was care coordination. Diagnosed in 2006 with metastatic squamous cell carcinoma of the head and neck, Walsh has undergone significant surgery, radiation and chemotherapy. Since

his diagnosis, his care team has grown, and communication had become a real challenge. He was dealing with a lot of pain from his cancer and was getting discouraged. On the advice of his primary care physician, Walsh began to see Quill, who helped coordinate and communicate with the other physicians involved in his care.

"It gets pretty complicated—different doctors, different therapies, everything," Walsh says. "To have somebody who knows all of that, who sees you as a whole person, is huge."

Walsh and his wife Nancy, who accompanies him to his appointments, really connected with Quill and appreciate his focus on their quality of life as individuals, as a couple and as a family.

Palliative care helped make some sense out of the storm that cancer brought to Walsh's life, forcing an early retirement and changing his plans for the future. It has helped the couple deal with grief, fear and frustration, and it has helped restore some of their control over a situation that had taken away so much.

"Palliative care didn't change the nature of the problem or the chronic nature of the disease, but it gave us hope," Walsh says.

It also gave the couple a chance to connect and communicate better. At their appointments with Quill, they feel comfortable enough to ask questions and share their concerns, big and small.

"I always feel we're heard when we're there," Nancy says. "I never feel that they're in a hurry—and sometimes it's a long appointment."

They have also seen how palliative care has translated into the way they relate to each other. They are no longer hesitant to bring up difficult topics such as whether to stop a particular treatment or planning for end-of-life care.

"You go through something like this, and you know it can either pull you apart or

bring you closer," Nancy says. "We've really come together through this."

The couple, who have been together for 45 years, are expecting their first grandchild this summer. They'd like to see the whole-person approach that typifies palliative care incorporated into other aspects of health care, especially with the growing number of baby boomers who are likely to need such services. They'd also like to see more people embrace palliative care as part of their treatment plans.

"It's not just about medical issues," Walsh says. "It's about bringing in good life experiences. It's leaving room to live your life a little." 

"Palliative care didn't change the nature of the problem or the chronic nature of the disease, but it gave us hope."

—Bob Walsh of Canandaigua

"We try to see what patients and families are in need of and tailor our conversation accordingly."

—Timothy Quill, M.D.

To learn more about palliative care, turn to page 14.



What is palliative care?

Palliative care is the medical specialty that focuses on the treatment of symptoms associated with serious illness, such as cancer, heart failure or neurological disorders. It is not the same as hospice care because it is given alongside any and all desired treatment for the underlying illness, and it can be incorporated as early as the time of diagnosis.

The goal of palliative care is to improve a patient's quality of life by addressing the symptoms and side effects of a serious disease and its treatment, as well as the emotional, social and spiritual issues that can arise with such a diagnosis. By design, palliative care is individualized, focusing on both patient and family, and it can include medications, nutritional guidance, physical or occupational therapy, massage therapy, spiritual care and other services.

Why do people confuse palliative care and hospice care?

Both palliative care and hospice adhere to similar principles of focusing on patient and family, providing comfort and support, and honoring a patient's goals and values. While palliative care can be given at any time during the course of illness alongside other desired medical treatments, hospice care is given when a patient is approaching the end of life, usually when the patient has a life expectancy of six months or less.

Who can benefit from palliative care?

Anyone with a serious illness such as cancer or heart failure is eligible for palliative care alongside their usual treatments. Often family caregivers benefit from the services as well.

Some of the indications that palliative care might be beneficial include:

- Pain and severe discomfort requiring symptom management
- Psychosocial, emotional, and/or spiritual distress
- Uncertainty about treatment options, goals of care or simply navigating the healthcare system
- Need for coordination of care



How do I connect with palliative care?

You, your family member or another health care professional working with you can request a palliative care consultation through your physician. To learn more about UR Medicine's Palliative Care Program, visit www.urmc.rochester.edu/medicine/palliative-care.

Wilmot, two hospitals to build regional cancer center

By Lydia Fernandez

This fall, construction begins on a new regional cancer center that will expand access to Wilmot Cancer Institute's services for patients in the Finger Lakes and Southern Tier.

The cancer center will be based at Noyes Health in Dansville, Livingston County, and will include services in Wellsville, Allegany County, and Hornell, Steuben County. It is a collaboration among Wilmot Cancer Institute, Noyes Health, Jones Memorial Hospital and UR Medicine Radiation Oncology.

A \$2 million gift from Ann and Carl Myers of Springwater, Livingston County, will be used to help construct the new facility and fund the establishment of care programs. The couple, who have supported other projects at Noyes, want to ensure that a full range of health care services remains available in their community.

"My wife Ann and I are grateful to be in a position to do this, and we think this cancer center will be good for anyone who lives in this area," Carl Myers says. "Whether you need to be treated for cancer or not, this will attract quality medical professionals to our community, and that will benefit everyone."

Each year, approximately 4,000 patients travel from Allegany, Livingston and Steuben counties to Wilmot Cancer Institute for outpatient care. They often make daily or weekly trips over a period of months to receive radiation and/or chemotherapy. The Myers Cancer Center will help alleviate the strain of traveling an hour or more for care.



The Ann and Carl Myers Cancer Center will be built on the campus of Noyes Health in Dansville.

Philanthropists Phil Saunders, left, and Carl Myers at the Myers Cancer Center announcement in April.

"We are grateful for the generosity of the Myers family and the commitment of these communities to support the creation of a regional cancer center," says Jonathan W. Friedberg, M.D., M.M.Sc., director of Wilmot Cancer Institute.

Plans for the cancer center and UR Medicine's regional cancer services in the Finger Lakes and Southern Tier include:

- A 4,500-square-foot, lower-level addition to house a radiation oncology clinic at Noyes Health in Dansville.
- A 2,300-square-foot medical oncology clinic in renovated and new first-floor space at Noyes.
- A medical oncology clinic will be established at Jones Memorial Hospital in Wellsville.
- UR Medicine's recently purchased radiation oncology practice in Hornell, which complements a medical oncology practice co-located in the same building.

The project has an estimated cost of \$8 million. UR Medicine, Noyes and Jones have agreed to contribute \$1 million assets to the cancer center project. In addition to the \$2 million gift from the Myers family, these three hospitals are encouraging

donors in their communities to support this effort.

"Noyes Health is excited to partner with Wilmot Cancer Institute and Jones Memorial Hospital to bring a comprehensive cancer program to the Finger Lakes and Southern Tier," says Amy Pollard, president and CEO of Noyes Health System. "This collaboration will expand access to medical oncology and radiation services, as well as support the mission of all of our organizations to improve the health of individuals in a compassionate and caring environment."

Construction on the campus of Noyes Health is expected to be complete by the end of 2016. The new medical oncology services in Wellsville will be available this fall.

"A regional cancer center is an example of how important it is for hospitals and health centers to form partnerships," says Eva Benedict, CEO at Jones Memorial Hospital in Wellsville. "It isn't feasible, or even realistic in the challenging financial environment that all health care facilities face, for each local hospital or provider to offer all the latest technology. By forming collaborations like this, we are able to ensure access to the highest quality specialty care, closer to home." 



Wilmot to help define future of molecular diagnostics for cancer

Jonathan W. Friedberg, M.D., M.M.Sc., director of Wilmot Cancer Institute, center, with Carl Morrison, M.D., DVM, executive director of the Center for Personalized Medicine at Roswell Park Cancer Institute and president, chief scientific officer and founder of OmniSeq LLC, and Candace Johnson, Ph.D., president and CEO of Roswell Park Cancer Institute.

Wilmot Cancer Institute has joined the OmniSeq Genomic Network, an organization of institutions being formed to help define the future of advanced genomic diagnostics for cancer. Through this network, Wilmot and Roswell Park Cancer Institute in Buffalo — the state's two largest cancer care and research institutions outside New York City — will collaborate and expand genomic testing for cancer across the Finger Lakes and western New York region. This network, which will create a database of genomic profiles of tumors, will also provide opportunities for research.

Genomic diagnostics allows physicians to examine the genetic makeup of cancer cells and identify mutations or other unique characteristics that can be matched with therapies known to be effective in treating such tumors.

"We're not just appreciating the genomic differences in cancer anymore," says Jonathan W. Friedberg, M.D., M.M.Sc., director of Wilmot Cancer Institute. "We have the capacity to act on them."

As part of the network, Wilmot will be able to use OmniSeq Target, a diagnostic test developed by the Roswell Park Center for Personalized Medicine, to analyze cancer-associated genes found in a patient's tumor. Members of the network will be able to develop a database of tumors' genomic profiles and other information that will help advance genomics in cancer care and allow researchers to learn more about cancer genomes and the influence of gene mutations.

"Wilmot and Roswell Park have a history of collaborating on cancer research, and through this network, we now will work together with other institutions to improve cancer care and pioneer this precision medicine technology for patients in our region," Friedberg says.

"Membership in the OmniSeq Genomic Network, which unites the resources and talents of outstanding institutions, will enable deeper, more clinically focused interaction between Wilmot and Roswell Park, magnifying the impact and reach of their efforts," says Carl Morrison, M.D.,

D.V.M., executive director of the Center for Personalized Medicine at Roswell Park Cancer Institute and president, chief scientific officer and founder of OmniSeq LLC.

OmniSeq LLC, a company formed in 2015 to commercialize the test, will offer OmniSeq Target and related services nationwide. OmniSeq Target will initially be used for non-small-cell lung cancer, the most common kind of lung cancer. The test will look at the 15 genes related to lung cancer and identify mutations for which there is an approved drug, an experimental drug or a drug for another cancer that can be used.

"Our participation in the OmniSeq Network extends our collaboration with the University of Rochester Medical Center in a wonderful new direction by making OmniSeq testing — a homegrown Western New York innovation — available to cancer patients across the region," says Candace S. Johnson, Ph.D., president and CEO of Roswell Park Cancer Institute. 

Wilmot board members leave legacy of leadership

Five members of the Wilmot Cancer Institute National Advisory Board finished their terms this spring:

- Steve McCluski of Pittsford, who served as the board chair from 2011 to 2014.
- Michael Donnelly of Penfield
- Janet Felosky of Naples
- Mark Kokanovich of Rochester
- Larry Rabinowitz of Rochester

They each joined the board in 2009. During their tenure, the board supported several significant projects including the James P. Wilmot Cancer Center building campaign and the vertical expansion of that building; the debuts of the Geriatric Oncology Program and the Judy DiMarzo Cancer Survivorship Program; the launch of

Michael Donnelly, left, Larry Rabinowitz, Janet Felosky and Steve McCluski completed five-year terms on Wilmot's National Advisory Board. Mark Kokanovich, not pictured, also completed his term.

the Wilmot Cancer Institute and the \$30 million research-focused campaign; and the robust regional expansion that is now underway.

"This work would not have been possible without the leadership of these dedicated individuals," says Richard DiMarzo, chair of the Wilmot board.



Planting Seeds of Hope nets \$81,000 for seed grants

For the third year, Wilmot Cancer Institute hosted Planting Seeds of Hope to raise awareness of and funding for seed grants to support cancer research. Held on Jan. 20 and 21, Planting Seeds of Hope highlighted Wilmot scientists and physicians whose research has been supported by seed grants. The event was featured during live broadcasts of 13WHAM News and on WBEE-FM radio. It drew more than 200 call-in donations and raised approximately \$81,000.

Each year, Wilmot Cancer Institute awards seed grants through a competitive process in the areas of basic, translational, behavioral or epidemiological cancer research.

"We are grateful for the more than 100 volunteers and many organizations who helped to make this event possible," says Tiffany Paine-Cirrincone, associate director, Advancement and Community Events for Wilmot. "We would also like to extend a special thank-you to the event's presenting sponsor, Kovalsky-Carr Electric Supply Co."

Planting Seeds of Hope will return in January 2016. To learn more, contact Paine-Cirrincone at (585) 276-4715.



At left, Aram F. Hezel, M.D., is interviewed by 13WHAM News about the importance of research at Wilmot Cancer Institute. Above, volunteers take calls from viewers during the Planting Seeds of Hope broadcast.



Wilmot honors grassroots group for supporting pancreatic cancer research

The Pancreatic Cancer Association of Western New York (PCAWNY) began with a chance meeting online six years ago. Three local women with loved ones facing this difficult cancer connected on a message board, and they resolved to find a way to help others and change the future of the disease.

Today, PCAWNY is a growing community force with dozens of members, including several long-term survivors. It connects and educates patients, families and physicians throughout the region, and it raises money that stays local. In doing so, PCAWNY has developed a close relationship with the Wilmot Cancer Institute and a handful of its researchers who are dedicated to pursuing new strategies to slow the disease and extend survival.

In recognition of the group's dedication and support, PCAWNY was honored with the Inspiration Award at Wilmot Cancer Institute's annual Discovery Ball on May 29, at the Hyatt Regency Rochester.

Since 2010, PCAWNY has raised more than \$320,000 to support cancer research in Rochester. With the work that was enabled by these funds, Wilmot researchers were able to secure a \$2 million grant from the National Cancer Institute. At the Discovery Ball, the group pledged another \$500,000 to support the development of the first-ever Pancreatic Cancer Center of Excellence in Rochester.

"PCAWNY has allowed us to understand this tough disease better by supporting our research," says Aram F. Hezel, M.D., chief of the Division of Hematology/Oncology at the University of Rochester Medical Center and a medical oncologist who treats patients with pancreatic cancer. "They have made Rochester a better place both for science and patient care, and on a deeply personal level, they help to sustain the energy and drive required to care for patients with pancreatic cancer and to dig deeper into the many questions this cancer poses."

Hartmut "Hucky" Land, Ph.D., Wilmot's director of research, right, presents the Inspiration Award to members of the Pancreatic Cancer Association of Western New York at the 2015 Discovery Ball with David C. Linehan, M.D., chair of surgery and Wilmot's director of clinical operations, far left.

be inspired

To see the story of the Pancreatic Cancer Association of Western New York and their support for research at Wilmot Cancer Institute, please visit <http://bit.ly/pcawny>.

To see photos from the 2015 Discovery Ball, please visit <http://on.fb.me/1J3UDHm>

Discovery Ball celebrates cancer research in Rochester

The 16th annual Wilmot Cancer Institute Discovery Ball raised more than \$480,000 to support seed grants for new and innovative cancer research initiatives. Akin to start-up funding in the business world, seed grants are one of the most powerful ways to advance promising research at Wilmot.

The event was co-chaired by Michael and Carolyn Linehan, who are among the third generation of the Wilmot family to support cancer research in Rochester. At the Discovery Ball, this generation of the family pledged \$350,000 to support seed funding.

Each year, Wilmot Cancer Institute awards seed grants to University of Rochester Medical Center researchers through a competitive process in the areas of basic, translational, behavioral or epidemiological cancer research. Seed funding helps enable researchers to attract national investment in their projects and helps Wilmot build research and clinical programs that draw national-level leadership and talent.



Carolyn and Michael Linehan

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Warrior Walk Brings Community Together for Cancer Survivorship

By Ruth Harper-Rhode

This year, 490 survivors, Wilmot Cancer Institute faculty and staff, family members and friends came out on a gorgeous summer day to the University of Rochester's River Campus for the Warrior Walk. The event, which featured sanctioned 5K and 10K races and a 1-mile walk, raised more than \$50,000 to support Wilmot's Judy DiMarzo Cancer Survivorship Program.

"With every step you walked or ran today, you have helped celebrate each survivor and all of those who are making a difference in their lives," Louis "Sandy" Constine, M.D., director of the survivorship program, told the crowd at the June 14 event.

More than 14 million cancer survivors are living in the United States today. By 2022, it is projected that there will be 18 million survivors. While it is hopeful and inspiring that more people are surviving longer after a cancer diagnosis, these survivors face new challenges, and helping them beyond the treatment stage has become a priority nationally and regionally at Wilmot Cancer Institute.

Wilmot's survivorship program is the first of its kind in the Rochester and Finger Lakes region, and it has so far helped more than 500 individuals navigate life after cancer.

"We know our patients will forever be affected by a diagnosis so we try to help them transition and find things that are meaningful to them now," says Alicia Coffin, MSN, RN, OCN, lead program coordinator of the Survivorship Program. "(We) help them get back to work if that's what they want to do, help them go back to school if that's what they want to do, connect them to specialists if they need it — find community resources, support groups, financial counselors, anything like that — so that patients can move on and have a life that is effective for them."

Each year, a select group of cancer survivors is honored at the Warrior Walk for their inspirational qualities and approach to living with cancer. This year's honorees include:

- **Tony DiGaetano**, who was diagnosed in 2003 with multiple myeloma. While cancer never totally goes from your mind, Tony says life is what you make it. "After you get diagnosed, you have to make a new you," he says. "You make your own opportunities."
- **Naomi Garwood**, who was diagnosed in 2012 with non-Hodgkin lymphoma. In treatment for two years, Naomi's mantra was to have "an attitude of gratitude for the big and small blessings of life."
- **Karie Kilner** and **Stacy Snyderman**, both breast cancer survivors who are advocates for those facing pancreatic cancer.
- **Karl Klein**, who was diagnosed in 2014 with lung cancer, and his wife **Debbie**. Throughout his treatment, Karl stayed upbeat. His outlook made a difference not only for him and his family, but also for the other patients and staff.
- **Bethany Marsh**, who was diagnosed in 2005 with acute lymphocytic leukemia. Today, she is the adolescent/young adult survivorship coordinator at Wilmot.
- **Cheri Struble**, who was diagnosed in 2012 with stage 1 invasive ductal carcinoma. Her experiences inspired her to open Comfort Caps, a boutique in Canandaigua that offers a variety of headwear and accessories for adults and children who have lost their hair due to cancer treatment.
- **Chris Wanjon**, who was diagnosed with squamous cell carcinoma of the tongue in 2009, and his wife **Jeanne**. They hosted a fundraiser to purchase two tracheotomy dummies — named Chris and Tommy Trach — for the post-surgical unit at the James P. Wilmot Cancer Center. 

Read more about the Warrior Walk honorees at bit.ly/2015WarriorWalk.





ABOUT THIS FEATURE

Every donor and community organization has their own reasons to give to cancer research. In this space in Dialogue, we'll share what motivates Wilmot Cancer Institute supporters.

Meghan Bucci, left, with Joseph G. and Elaine Bucci, who have committed \$1 million to support breast cancer research at Wilmot Cancer Institute.

At the crossroads of philanthropy and science: Joseph G. and Elaine Bucci

For Joseph G. and Elaine Bucci, the key to changing the future of breast cancer is the research that is underway today.

The Buccis, whose families have been in Livingston County for generations, have seen many of their loved ones face the disease.

Just last year, four members of their family, including their daughter-in-law Meghan Bucci, were being treated for breast cancer at the same time.

They have also seen the difference that research has made in improving the effectiveness and reducing the side effects of treatment.

"Because of research, breast cancer care has improved so much and the effects of chemotherapy and radiation have become less debilitating," Elaine Bucci says. "In order for treatments to continue improving,

we need to support research."

Earlier this year, the Buccis, who have long been supporters of Wilmot Cancer Institute, committed \$1 million to support breast cancer research at Wilmot. Even with so many large organizations nationwide dedicated to supporting breast cancer research, the Buccis wanted to keep the funds where they could make the most difference for their friends and family.

"By giving locally, we can have a greater impact on breast cancer care and research in our community," says Meghan Bucci, who was diagnosed in 2014 at age 37 and who has two young children.

"My hope is that a cure is found through continued research before my granddaughter Olivia grows up," Elaine Bucci says.

The Buccis are devoted to their family and to their community. Joseph Bucci is

the co-founder and co-CEO of American Rock Salt Co., the world's second-largest salt mine. He is a former history and social studies teacher, as well as a high school football coach. Elaine Bucci, a former sixth-grade teacher, is involved with many community activities in Livingston County.

"Philanthropic support for breast cancer research is critical at a time when federal funding for cancer research has diminished," says David C. Linehan, M.D., co-director and director of Clinical Operations at Wilmot Cancer Institute. "This generous commitment from the Bucci family will guarantee that women in our region will benefit from access to state-of-the-art clinical and scientific research here at the Wilmot Cancer Institute. Gifts like this can provide the spark that generates significant advances that improve outcomes and directly impact the lives of our patients." 



Stacey Bolger and his family donated \$2,507 to Wilmot Cancer Institute. Last fall, they held their annual "Stand Against Cancer," a front-yard farm stand where they sold pumpkins, corn stalks, gourds and other items. They donated the proceeds to Wilmot, and they encouraged donors to sign a beautiful hand-painted "Stand for Cancer" sign to show additional support for cancer patients.

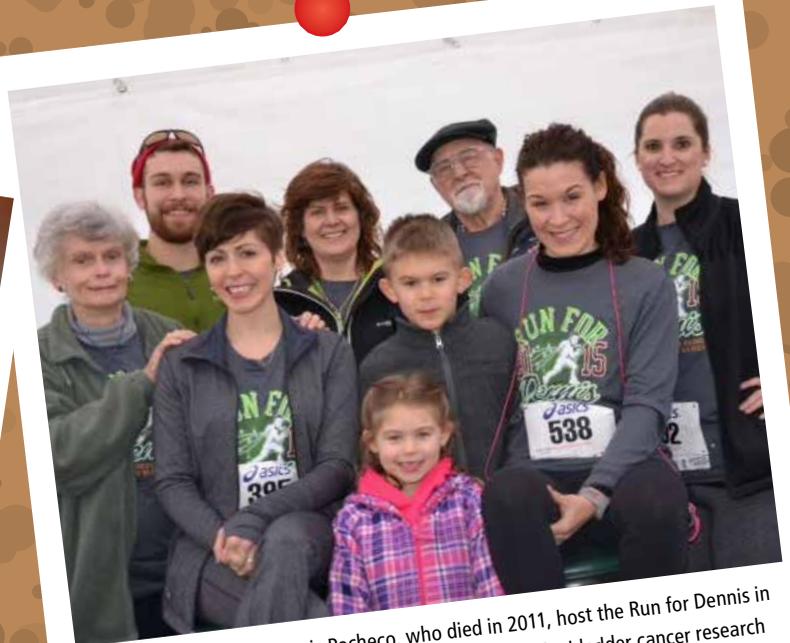
Community-organized events like these are important to Wilmot Cancer Institute and to the community. From golf tournaments to fashion shows, pasta dinners to pong tournaments, these events raise funds that allow Wilmot to continue its research and provide precision care.

Whether remembering or honoring a loved one who has been affected by cancer or just trying to make a difference for our community, these events reflect the heart of Wilmot's mission.

If you have any questions about third-party community events or would like to talk with someone about starting one, please contact Tiffany Paine-Cirincione at tiffany.paine@rochester.edu or (585) 276-4715.



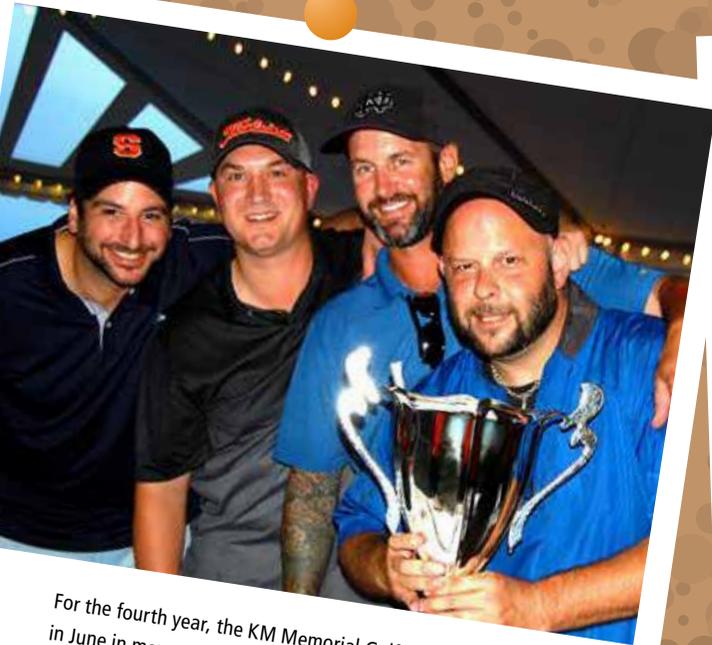
Keeping the Hope Alive, an event held Feb. 8 at Flaherty's in Macedon, raised \$6,000 for breast cancer research at Wilmot Cancer Institute. Paula Bokman, a breast cancer survivor, and Blanche Shearer, led the efforts. Keeping the Hope Alive has raised more than \$64,000 since its first event nine years ago. This year, three breast cancer survivors were honored and more than 100 people attended.



Family and friends of Dennis Pacheco, who died in 2011, host the Run for Dennis in his honor each March in Oswego. This 5K raises funds for bladder cancer research performed by Edward Messing, M.D., at Wilmot Cancer Institute. This year, Dennis' family donated \$5,000 to Dr. Messing's urologic oncology fund.



STEEL Lillies formed in January 2012 as a way for Tiffany Lill to raise awareness and funding for sarcoma research. Lill passed away from sarcoma in April 2012 but the group has held events to continue the efforts she started and to honor her memory. On May 31, the fourth and final STEEL Lillies 5K took place in Webster. The group achieved their goal of raising \$250,000 for sarcoma research at Wilmot Cancer Institute.



For the fourth year, the KM Memorial Golf Tournament took place in June in memory of Kathleen Myzrwka, who was diagnosed with glioblastoma in February 2011. Kathleen died in April 2012, and her son, Mike, held the first tournament four months later. This year, the event raised \$5,000 that will benefit brain cancer research at Wilmot.



In May 2013, Theo Bullock, a devoted teacher, was diagnosed with breast cancer. Her journey was challenging, and luckily she had the support of her community to help her through. Six of her former students planned a walk in her honor that drew more than 150 people. The event, dubbed "Around the Block for Bullock," was held in Belmont, Allegany County, and raised nearly \$3,000 to support breast cancer research at Wilmot.

CALENDAR OF COMMUNITY EVENTS

Sept. 12
13th Annual Steve Coleman Memorial Golf Tournament: Proceeds will benefit Wilmot Cancer Institute's Research Fund. The tournament will take place at Chili Country Club starting at 8 a.m. For more information, contact Tiffany Paine-Cirrinicone at (585) 276-4715.

Sept. 14
Second Annual Ray Dutcher Memorial Golf Tournament: This tournament has a 12:30 p.m. shotgun start at Webster Golf Club. Proceeds will support brain cancer research. To learn more, contact John Gramlich at jgramlich1126@gmail.com.

Sept. 24
Adding Candles for a Cure: Guests will enjoy hors d'oeuvres, an auction, a champagne toast, cake raffle, candle-lighting ceremony, and coffee and dessert, all while raising funds for brain cancer research at Wilmot Cancer Institute. The event takes place from 6 to 9 p.m. at Midvale Country Club in Penfield. To learn more or purchase tickets, visit addingcandles.com/cake-sale/.

Oct. 1
Dado Fashion Show: Save the date for the 2015 Dado Fall Fashion Show at The Strathallan Hotel's rooftop bar in Rochester. Proceeds will benefit Wilmot Cancer Institute. To learn more, contact Tiffany Paine-Cirrinicone at (585) 276-4715.

Oct. 3
8th Annual Coop Cup: Come out for a day of golf at the Mill Creek Country Club and support research for brain cancer. To learn more, contact Josh Kent at joshdkent@gmail.com.

Oct. 24
7th Annual Scare Brain Cancer Away: This 5K run/walk at East Rochester High School starts at 9 a.m. Post-race refreshments will be available, and some proceeds from the event will benefit brain cancer research at Wilmot Cancer Institute. Learn more at pcr-timing.com/2015.html#scare or by contacting Paul or Margy Richards at (585) 381-7978 or mpaul@pcr-timing.com.

Nov. 11
Step It Up! Cure Pancreatic Cancer Walk: Join the Pancreatic Cancer Association of Western New York (PCAWNY) at the RIT Gordon Field House starting at noon. Proceeds support PCAWNY and pancreatic cancer research at Wilmot Cancer Institute. Learn more at pcawny.org or contact Mary Ellen Smith at mesmith@pcawny.org.



Stay Up To Date on Community Events

Looking for the most recent information on community events that support Wilmot Cancer Institute?

Visit us at [Facebook.com/WilmotCancerInstitute](https://www.facebook.com/WilmotCancerInstitute) or <http://bit.ly/WCevents>.



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On July 31, Wilmot Cancer Institute hosted Survivors Night at Frontier Field in Rochester to celebrate cancer survivorship. More than 1,000 survivors, caregivers, families, friends, staff and supporters turned out for a great night of Red Wings baseball.

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