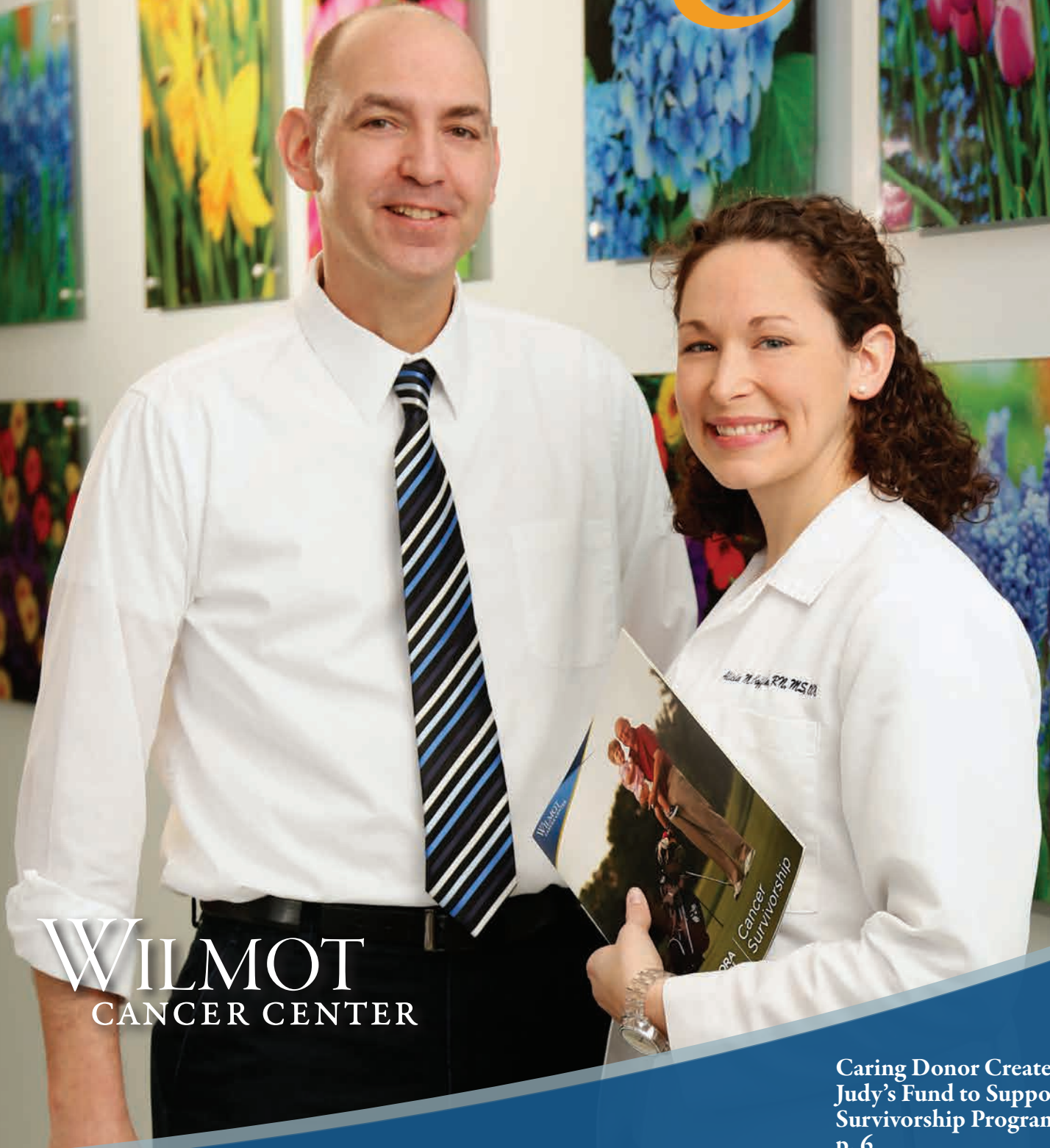


Spring 2013

# Dialogue

James P. Wilmot Cancer Center | University of Rochester Medical Center



**WILMOT**  
CANCER CENTER

**FACES OF CANCER  
SURVIVORSHIP**

**Friedberg  
Named Director  
of Wilmot Cancer Center**

**Caring Donor Creates  
Judy's Fund to Support  
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a National Leader in  
Survivorship Research  
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# Letter from the CEO



In this issue of *Dialogue*, I am delighted to announce the appointment of Jonathan Friedberg, M.D., M.M.Sc., as Director of the James P. Wilmot Cancer Center. He replaces Richard I. Fisher, M.D., who stepped down last summer after leading Wilmot for 11 years.

Dr. Friedberg was recruited to the Medical Center by Dr. Fisher more than a decade ago. After graduating from Harvard Medical School and completing his internship and residency at Massachusetts General Hospital, he completed medical oncology and hematology fellowships at Dana-Farber/Partners Cancer Care. He joined Wilmot in 2002 and was named chief of the Division of Hematology/Oncology in the Department of Medicine in 2009.

Among those who've worked with him, Dr. Friedberg has become known as an academic and clinical leader of exceptional vision and talent. He leads with warmth and respect for those around him, while at the same time driving multiple initiatives forward at a rapid pace. I have no doubt that Wilmot's broad mission – to deliver the most advanced cancer care, to expand the reach of our services regionally, and to be a leader in cancer research – will thrive under his leadership.

In addition to announcing Dr. Friedberg's appointment, we have reaffirmed the 2012 appointment of Hartmut "Hucky" Land, Ph.D., as Director of Research and Co-director of the Wilmot Cancer Center. A basic scientist who has served as the founding chair of the Department of Biomedical Genetics since 2001, Dr. Land has contributed key discoveries about the ways that gene mutations cooperate within cells to initiate cancer. As Wilmot's Director of Research, he is working with Dr. Friedberg to develop the center's research strategic plan.

Wilmot's greatest strength is that we have clinicians and researchers working together, studying cancer and applying the latest scientific knowledge to the care of every patient. Together, Dr. Friedberg and Dr. Land will nurture those interactions so that we deliver the highest quality of care for our patients.

That's medicine of the highest order. Our community deserves nothing less.

Sincerely,

A handwritten signature in black ink that reads "Bradford C. Berk". The signature is fluid and cursive, with a large initial 'B'.

Bradford C. Berk, M.D., Ph.D.

CEO, University of Rochester Medical Center

## On the Cover

Cancer survivor Shannon Case and Alicia Coffin, MS, RN, OCN, lead nurse for Wilmot's new clinical cancer survivorship program.

photo by Ken Huth

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## Letter from the Director



# SURVIVORSHIP

Dear Friends of Wilmot Cancer Center,

One of the most wonderful challenges oncologists and primary care physicians face today is managing the ongoing healthcare needs of a rapidly expanding population of cancer survivors. As we continue to make gains in research and clinical care, the ranks of cancer survivors swell, with the U.S. population of cancer survivors now at more than 12 million – and growing every day. While the very good news is that these patients are winning their battle with cancer, they still face a lifetime of potential health concerns related to their disease and their treatment therapies.

These survivors deserve to have the fullest, healthiest possible life after their cancer care. The Wilmot Cancer Center has long been concerned with life after cancer and been a national leader in studying and researching survivorship issues. In 2007, Wilmot Cancer Center physicians and scientists convened a national Cancer Survivorship Research and Education workshop right here in Rochester, drawing experts from across the nation. We have built a world-class research program in cancer survivorship and now, thanks to a generous gift from Richard DiMarzo, we are able to launch a clinical program in survivorship. In keeping with our commitment to a multidisciplinary model of care, the program is led by Drs. Louis Constine (radiation oncology), Michelle Shayne (medical oncology), Eva Galka (surgical oncology), and Alicia Coffin, R.N. Our goal is to bring the world's best research on cancer survivorship into the hands of patients and primary care physicians.

The effects of cancer treatment can be far-reaching, and dependent upon many factors: the type and progression of disease, length of treatment, and the ever-evolving drugs and therapies used. Making health care decisions after cancer care can be incredibly complex, but our new effort will help individuals by providing them with a post-treatment road map for life after their care.

Our program will provide a needed resource for our region by providing patients who complete their cancer treatment with two concise, portable documents: the care plan and the treatment summary. Our ultimate goal is to provide this service to patients who were treated elsewhere, and to offer educational seminars for referring providers and primary care physicians to bolster their understanding of the needs of our population of cancer survivors. I am proud of this important initiative and how it truly represents "Medicine of the Highest Order."

Finally, on a personal note, I would like to thank Medical Center Leadership for providing me the opportunity to serve as Director of the Wilmot Cancer Center. Over the past several months, as Acting Director, I have experienced the outstanding support of the faculty, staff and entire Rochester community. The very creation of the clinical survivorship program is only one example of generous support of time and resources by the community, which not only sustains the Cancer Center, but positions us for greatness. Over the next several months, we will complete our strategic planning process, and I look forward to sharing with you our developing plans for research, clinical care and community engagement. Our research collaboration with Roswell Park Cancer Institute, the recent merger with the Pluta Cancer Center, and other regional alliances position us extremely well for the uncertain future of health care reform. I'm blessed with an outstanding leadership team, including Director of Research and Co-Director Hartmut Land, Ph.D., Associate Director of Administration Brian Martin, and Associate Director of Clinical Services Patti Murray. I look forward to working with them, and all of you to further our mission of providing nationally recognized clinical care and cancer research of the highest quality.

Sincerely,

A handwritten signature in black ink that reads "Jonathan W. Friedberg, MD".

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

Director, James P. Wilmot Cancer Center

# Survivorship Program Launches to Help Patients Improve Post-Treatment Quality of Life

For decades, physicians and scientists at the Wilmot Cancer Center have forged a legacy in research related to cancer survivorship.

At right, Cancer survivor Shannon Case consults with Alicia Coffin, M.S., R.N., O.C.N.



## SURVIVORSHIP

With roots that stretch back to the groundbreaking research of Phil Rubin, M.D., who earned international recognition for his study of the effects of radiation exposure, and for whom the research-focused Center for Cancer Survivorship at URM is named, Wilmot scientists have brought the institution to the forefront of survivorship research.

Now, thanks to the work of a multidisciplinary team of physicians and the generosity of a caring donor, the seeds of a clinical cancer survivorship program planted many years ago have now come to fruition and Wilmot once again leads the way with the launch of a clinically based cancer survivorship program. Directed by Louis "Sandy" Constine, M.D., and co-led with Michelle Shayne, M.D., Eva Galka, M.D., and Alicia Coffin, M.S., R.N., OCN., the program is the first of its kind in the region. The program has benefitted from the strong support of Richard DiMarzo, who established "*Judy's Fund: Hope for Cancer Survivors*" with a gift of \$1 million

in memory of his wife, Judy, who lost her nine-year battle with lymphoma in 2009.

"As a regional leader in cancer care and research, we have to be constantly evolving as a cancer center and find new ways to raise our level of care for our patients," said Jonathan Friedberg, M.D., MMSc, director of the Wilmot Cancer Center. "We've become a destination point for talented researchers, clinicians and patients from beyond our region in large part because of our ongoing mission to constantly seek ways to improve. A clinical cancer survivorship program, which builds on the success of our research in that area, is a logical progression for us and a wonderful benefit for our patients. We are extremely grateful to Richard DiMarzo for his support in starting this program. While his gift is certainly extraordinary, I am even more moved by his passion for the program and his sincere desire to create a better life for cancer survivors."

Factors such as breakthroughs in research and treatment, earlier detection and more accurate diagnoses have resulted

## How do we define a “Cancer Survivor?”

There has been a lively debate in oncology circles about an appropriate definition of “cancer survivor,” including a lengthy discussion in a very recent issue (Feb. 1, 2013) of the *Journal of Clinical Oncology*. The prevailing thought is that the term “cancer survivor” applies to anyone who has been diagnosed with cancer, from the time of diagnosis through the balance of his or her life.

### Survival statistics

The National Cancer Institute estimates that there are approximately 13.7 million cancer survivors living in the United States today. The vast majority of cancer survivors come from a pool of four of the more common cancer types. According to a recent American Cancer Society report, 22% of survivors living

today were originally diagnosed with breast cancer, 20% had prostate cancer, 9% had colorectal cancer, and 8% had a genitourinary form of cancer, such as uterine, ovarian, and cervical cancers.

Surging survival rates are often attributed to the following:

- The most common forms of cancer from where survivors emerge have experienced improved screening measures, leading to earlier detection. These include mammography for breast cancer, the prostate specific antigen (PSA) test for prostate cancer, the Pap test for cervical cancer, and colonoscopy for colorectal cancer.
- Development of more effective treatments.
- Improved management of treatment side effects, allowing physicians to take more aggressive measures and provide higher, more effective doses of cancer drugs.

- Disease-specific, targeted therapies have become a new, more effective weapon. These therapies are designed to attack cancer cells while doing less harm to normal cells, and are often less toxic than standard chemotherapy.

**Of the 11.7 million people living with cancer in 2007—**

**7 million were 65 years of age or older.**

**6.3 million were women.**

**4.7 million were diagnosed 10 years earlier or more.**

Source: American Cancer Society

in the number of cancer survivors growing at an accelerated pace. According to the most recent figures provided by the U.S. Centers for Disease Control (CDC), the number of cancer survivors in the United States increased from just three million in 1971 to 9.8 million in 2001, and then to 11.7 million just six years later in 2007. The National Cancer Institute recently estimated that 13.7 million people with a previous cancer diagnosis are living in the United States today. In addition, more people are living a longer period of time after diagnosis. About two out of every three people diagnosed with cancer are expected to live at least five years after diagnosis. The most recent CDC numbers indicate more than a million people were alive in 2007 after being diagnosed with cancer 25 years or more prior.

Clearly, the growing numbers of survivors is a sign of the tide turning in what is often termed the war on cancer. However, these patients often take with them a host of lifetime health issues, often referred to

as late effects – including a higher risk of cancer recurrence, heart disease, and other physiological and emotional concerns that require carefully coordinated monitoring and care, involving their primary care physician and their oncologists.

“Living beyond cancer should be cause for celebration for the growing numbers of individuals who have prevailed and survived treatments,” said Conline, a professor of radiation oncology and pediatrics who has written extensively on the topic and traveled the world to lead discussions and task forces on survivorship issues and late effects of treatment. “Unfortunately, each day is far from a celebration for many survivors. Many have physical problems, financial obstacles, and mountains of emotions that must be conquered. All of these hurdles can compromise the quality of life of cancer survivors and their family. They deserve our help in overcoming these hurdles.”

“I think the survivorship program’s impact on patients will be tremendous,” said Michelle Shayne, M.D., one of the

leaders in the development of the program. “Research in survivorship demonstrates that patients want to be given a summary of their cancer treatment. Patients with whom I’ve spoken have questions about their follow up in terms of which studies are appropriate for surveillance and how frequently these should be done. It’s fine to give a verbal response to these questions but it’s so much more meaningful to give this information to patients in writing. To give them a document they can use to discuss their care with their primary care doctor or family members. This document can serve as a terrific resource if a patient can’t remember a particular recommendation or if a patient is moving to another city or transferring care.”

### What are Late Effects?

A late effect is a delayed or long-term effect that patients may experience following treatment of their cancer. They are essentially side effects of the cancer itself or the aggressive treatments needed



Michelle Shayne, M.D., Louis "Sandy" Constine, M.D., and Eva Galka, M.D.

to rid the body of cancer cells, including chemotherapy, radiation therapy, and surgery. Radiation to the chest area, for example, can impair future heart or lung health, as can chemotherapy. Osteoporosis, chronic fatigue, emotional difficulties and a higher risk of developing a secondary cancer represent a sampling of other noted late effects of treatment. The experience for each patient may be very different, and some patients can be more vulnerable than others. Because, fortunately, cancer patients are now living much longer, managing these late effects has become increasingly important because health providers want to do whatever possible to improve and optimize the quality and duration of life for their patients.

### **Survivorship Program Goals**

"Patients have many questions when first diagnosed with cancer," Constine said. "Often, patients have even more questions after completing treatment. They want to know how often follow up visits should occur, what tests should be done to make certain the cancer has not recurred, or what the signs and symptoms of recurrence might be, and what should trigger a phone call to a doctor between scheduled visits. They are also appropriately concerned about the possible long-term effects of the treatment on their health and how they can best be protected."

The multidisciplinary team behind the Wilmot Cancer Center's clinical survivorship program is dedicated to helping patients navigate through the complexities of

survivorship care and to answering the many questions they may have.

In order to make lifelong follow-up care and monitoring easier and more effective, all patients who receive treatment will be given a written summary of their treatment and care plans. Treatment summaries contain detailed information about the specific cancer diagnosis and disease stage along with information about the various types of treatment received, such as surgery, chemotherapy, and radiation therapy. The physicians who have prescribed the treatments and performed any surgery are listed by name along with their contact information, as well as the specific dates of treatment.

Other members of the care team are also listed, including physical therapists, fertility experts, and social workers. Care plans

## To learn more about the Wilmot Cancer Center's survivorship program, call (585) 275-6956 or visit [Survivorship.urmc.edu](http://Survivorship.urmc.edu)

are personalized documents that include information about how frequently follow-up visits should take place. These documents include a list of important surveillance tests along with the recommended frequency of testing. Important signs and symptoms of disease recurrence along with possible late effects of treatment are contained in the document as well. There is also useful information in the care plan pertaining to diet and exercise. Care plans keep patients and their referring physicians informed and involved in their ongoing care.

If problems develop in the months to years following cancer treatment, the survivorship program has a panel of specialists who are ready to see patients right away. These specialists are experts in survivorship care with a clear understanding of the effects of cancer treatment. The program is built upon treatment summaries and evidence-based survivorship care plans that will be distributed to patients, private care practitioners, and oncologists to facilitate a partnership between all parties.

### **The Transition to Cancer Survivor**

Presently, each of the disciplines of oncology (radiation oncology, medical oncology, and surgical oncology) has at least one nurse coordinator who closely works with his/her respective physician and the entire multi-disciplinary team during a patient's active phase of treatment, a fundamental aspect of care that will not change. However, under the leadership of Alicia Coffin, MS, R.N., OCN, newly named lead nurse of the survivorship program, at least one nurse from each cancer subspecialty, such as lymphoma, breast cancer, head and neck cancer, etc., will be working in newly developed survivorship clinics, facilitated primarily by nurse practitioners (NP's), to initiate the process of transitioning the patient from active treatment to survivor. This is ideal given that this nurse, the nurse practitioner, and the patient would have already developed a close relationship

during the months of active therapy.

"Alicia's role is critically important because she is the Nurse Leader dedicated to our survivorship program and the growing population of patients who are cancer survivors," Friedberg said. "She has been instrumental in organizing the program and the documents we provide to patients and their primary care physicians. She will coordinate the actual process of patients' after-treatment transition meeting, during which we discuss a summary of their treatment, necessary follow up care, possible needs of the patient, and the resources available to meet those needs."

The transition nurse will be responsible for reviewing the individual survivor's treatment history and providing a customized treatment summary and survivorship care plan (SCP), which will be handed to and reviewed with the patient and the survivorship nurse navigator at the transition of care visit. This visit will also be important to address other needs or concerns emotionally, physically, financially, as well as an opportunity to discuss nutrition, exercise, complementary medicine, etc. Resources and referrals will be provided based on these needs. This nurse will also collaborate with the patient's primary care physician and review the SCP to coordinate continuity of care.

"This is an exciting opportunity for me because I have always been passionate about oncology care and working with cancer patients," Coffin said. "We do a great job following our patients very closely during treatment and attending to the needs that they have at that time. This program will allow us to continue to provide excellent care and give support and resources to our patients who have completed treatment and are looking to move forward past cancer and lead healthy lives."

Wilmot Cancer Center fellows and residents have also played an important role in developing documents and protocols

related to care for cancer survivors. Shayne, a medical oncologist specializing in breast cancer, had piloted an educational study in survivorship that introduced the basics of cancer survivorship care to trainees in the Hematology/Oncology and Radiation Oncology programs. The pilot study used a curriculum based on survivorship literature compiled by Shayne.

"Our Hematology/Oncology fellows and Radiation Oncology residents are playing a leading role in the development of treatment summary templates and quality care plans," said Shayne. "These documents are being integrated into our electronic medical record for eventual dissemination to all patients treated at the Wilmot Cancer Center. While our fellows and residents are assembling these important components of cancer survivorship care, they are also learning about survivorship."

"This is all part of our novel educational initiative called the Cancer Survivorship Workshop," Shayne continued. "It's so important that we train the cancer specialists of the future to be prepared to manage the unique needs of survivors. The population of cancer survivors is growing exponentially and graduates from our Hematology/Oncology and Radiation Oncology training programs are ready to incorporate expertise in survivorship into their medical practice."

Constine was quick to point out that the development and implementation of the new survivorship program was successful only because of the involvement of a broad range of contributors.

"I think it is critical to recognize the fact that we have a large team dedicated to achieving our goals, and these team members represent all disciplines and divisions – from physicians to nurses to e-record personnel. It is this collection of professionals who are passionate about survivorship support that helps ensure our success. Moreover, it is our patients that lead our way, that inspire us to do this work, and that support our efforts." **wcc**

# Judy's Fund Creates Legacy of Caring and Support for Cancer Survivors



*Judy's Fund*  
HOPE FOR CANCER SURVIVORS



Paul Hanrahan, a close friend of Richard and Judy DiMarzo and board member of Judy's Fund, speaks at a kick-off event for the fund.



Judy DiMarzo

While more and more individuals diagnosed with cancer join the ranks of cancer "survivors" rather than "victims," many will face a lifetime of health challenges – both physical and emotional – as a result of their cancer treatment. Thanks to the generosity of a caring donor, Wilmot Cancer Center patients will now have a formal plan in place to deal with those issues. Richard DiMarzo, inspired by the brave, spirited fight of his late wife, Judy, who lost a nine-year battle with lymphoma in 2009, has stepped forward to help Wilmot Cancer Center physicians and staff provide for the unique needs of patients who have survived cancer.

In honor of Judy, and in grateful

acknowledgement of the excellent care she received while a patient at Wilmot, Richard has contributed \$1 million to establish **Judy's Fund: Hope for Cancer Survivors**, which provides the necessary support for the Cancer Center's new clinical Survivorship Program, designed to improve the quality of life for the growing number of cancer survivors in the greater Rochester region.

The gift represented a slight change of plans for Richard, who initially was considering waging a battle against the disease that claimed his wife of 38 years.

"I found that anger initially lead me to make the initial pledge for lymphoma research," the Rochester native said. "I felt

overwhelmed when I lost Judy so I struck out against the disease that caused my pain, wanting desperately to have someone provide a solution which I couldn't provide. But when I took a step back and looked at Judy's life and the way in which she lived through her journey, I understood that Cancer Survivorship best exemplified her life. Judy lived her life with hope for herself, her family and for those around her."

For years, Wilmot physicians have been building a framework for a clinical survivorship program and were ramping up related discussions with the center's National Cancer Advisory Board. For Richard, the discussions were a cue to become more deeply involved.



Sons Brian and Josh, with their wives Mary and Amanda, at the Discovery Ball with Judy and Richard DiMarzo.

"At the first event we held to announce the cancer survivorship program, a woman who happened to be a cancer survivor exclaimed during the question and answer session, *'I don't have a question, I have a comment. I've been waiting for this for a long time!'* I knew there was a need and I knew it fit URMCC's long range plan to take on a more regional approach to medicine," Richard says.

The DiMarzo's close association with the Wilmot Cancer Center began in 2001, when Judy was diagnosed with lymphoma. She and Richard decided to seek a second opinion at Wilmot when they were told at another local hospital where Judy was initially treated that she may eventually need to be referred to Wilmot for a possible bone marrow transplant.

Richard recalls a simple gesture of an oncology fellow at their initial visit who, when Judy asked if he had time for a few more questions, closed his chart and told Judy he had all the time in the world for her. For Richard, it was a pivotal moment in his desire to become more involved with the cancer center. Both were moved by the

caring and dedicated providers who assisted them throughout Judy's journey.

"The most meaningful things in life are time and health," Richard said. "When someone can sit back and say 'I have all the time in the world for you', you set yourself apart from all the others. I immediately knew Judy was at home."

A Senior Vice President and Senior Portfolio Management Director at the Pelican Bay Group at Morgan Stanley Smith Barney, LLC. in Pittsford, Richard subsequently served as a member of the Corporate Underwriting Committee and the Steering Committee for the annual James P. Wilmot Cancer Center Discovery Ball, the center's marquee fundraising event. In 2011, he was elected to the cancer center's National Cancer Advisory Board, where he currently serves on the board's Executive Committee.

Still, Richard wanted to do more. In discussions with Wilmot leadership, he asked how he could use philanthropy to make a significant, positive impact for cancer patients. Jonathan Friedberg, M.D., MMSc, director of the Wilmot Cancer Center,

informed Richard of the center's desire to establish a clinical survivorship program that would help guide cancer survivors through a lifetime of related health issues that could be successfully addressed with a detailed care plan. With a rich and storied history in survivorship research, the Wilmot Cancer Center still lacked a clinical program, and had been working for several years to develop one. With his gift to establish *Judy's Fund*, Richard provided the final support mechanism to help launch the clinical program.

"The impact of Richard's gift will be felt by cancer survivors in our community for decades to come," said Friedberg. "So much effort has been focused on the frontline battles with cancer that it has been easy to look beyond the ongoing needs of cancer patients once they have won those battles. We're deeply grateful for his support, and for the establishment of *Judy's Fund*, because we know it will immensely improve the quality of life for cancer survivors throughout our region."

Through the support of *Judy's Fund*, the survivorship program serves as a clinical

resource to help educate patients and primary care physicians about the after-effects of cancer treatments while also providing treatment resources to improve the quality of life for the expanding community of cancer survivors.

*Judy's Fund* contributes to:

- The development of care plans for specific cancers and treatments that are informed by leading-edge research.
- Funding educational visits for cancer survivors to review their care plans and treatment summaries.
- Educational initiatives in the region to help primary care providers gain information about to best care for cancer survivors.

In addition to his gift to establish *Judy's Fund*, Richard has been blessed to attract the support of several friends in the community to help ensure the long-term success and impact of the fund. Some of those who have become more intimately involved are close friend and business associate Paul Hanrahan, Professional Alliance Group Director and First Vice President at the Pelican Bay Group, and Paul's wife, Katy. Paul serves as spokesperson for, and board member of *Judy's Fund*, and joined the National Cancer Advisory Board of the Wilmot Center in 2012.

Paul and Katy have been instrumental in helping Richard organize a number of community fundraisers, ranging from a pig roast that raised several thousand dollars for the fund, to planning an upcoming Survivors' Night at a Rochester Red Wings game this summer. Richard points to their involvement as being a true gift for him and Judy, and central to the success of *Judy's Fund*.

"During Judy's final weeks Paul became more than a partner," Richard recalls. "He and Katy truly have become two of my closest friends. Judy and I were very fortunate and, as such, I was able to create *Judy's Fund* so others may benefit and may know her as I did. But it's Paul and Katy who are the heart of the fund. They provide its life."

"Katy and I deeply value the friendship we have had with Judy and Richard," said Paul Hanrahan. "During Judy's treatment of her cancer, she and Richard were incredibly caring and supportive of me and my family as we lived through our own struggles with the disease. It gave us the strength to keep fighting. Richard's generosity and commitment in establishing *Judy's Fund* is not surprising to those who know him and know of the love he had for his wife. I cannot express in words the heartfelt satisfaction we have in being a part of this great work."

A graduate of Colgate University, where he earned a Bachelor of Arts degree in Philosophy and Religion, Richard is also involved in supporting several other Rochester-area organizations. He serves on the Finance and Property committee, as well as the Investment Committee for the Colgate Rochester Crozier Divinity School, where he was also recently elected as a Governing Trustee to the board. His passionate support of Wilmot is clearly evident in his words and actions.

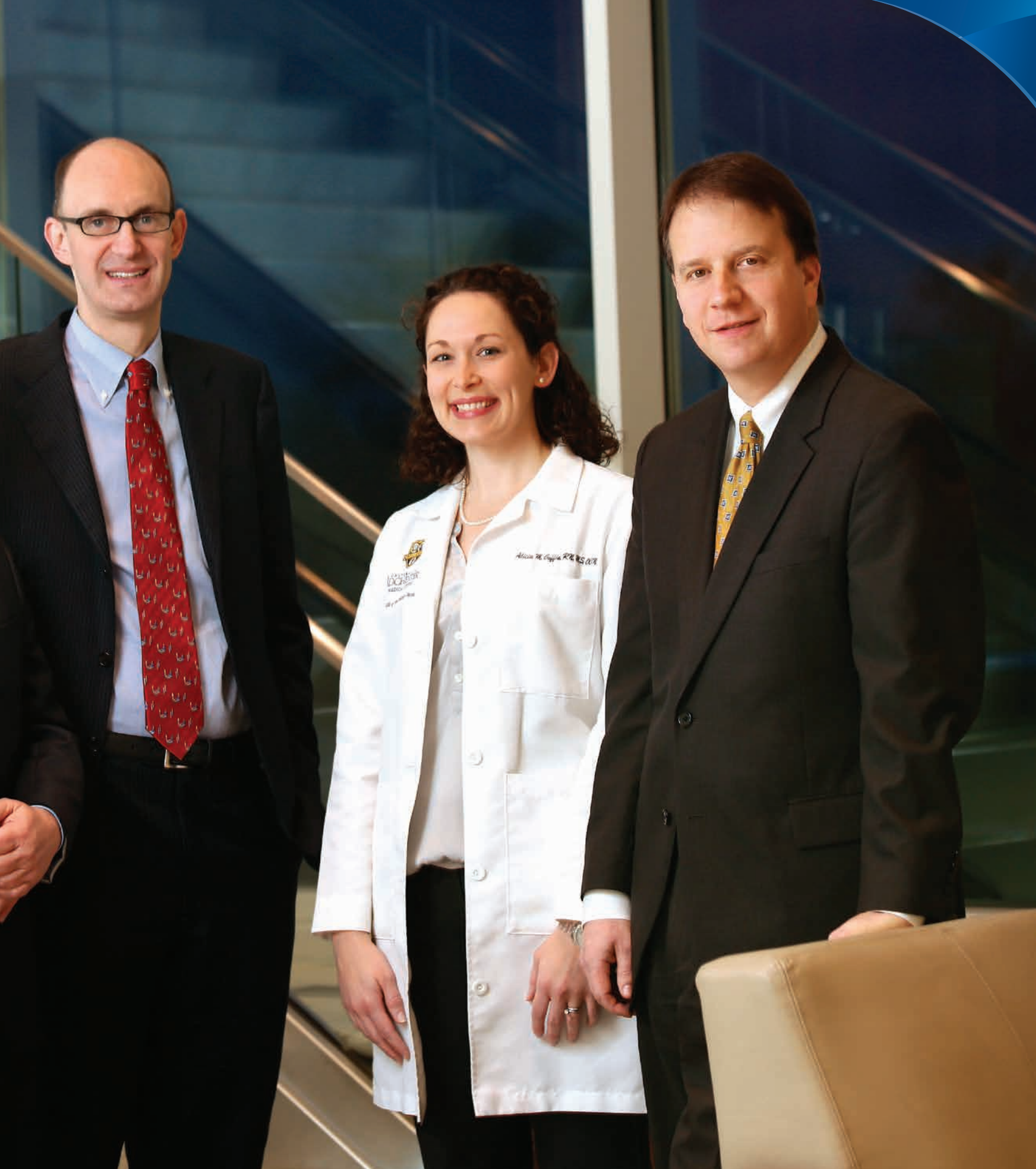
"Success has allowed me and my late wife Judy to make a wonderful gift to others," Richard says. "But all of us need to understand that a gift is a special ability to do something. Whether it is donating \$1, \$10, or thousands, or simply volunteering your time, gifts are always welcome and come in many ways because they come from the heart. No one should ever feel the lesser no matter what they give."

"I always remind myself of Wilmot's slogan, 'The Cure Starts Here.' To me that says dedication.

When you drive down Elmwood Avenue or Crittenden Boulevard, you can be overwhelmed by size of UPMC and Wilmot. And when you enter the building it can seem daunting. But when you realize that everyone at Wilmot is dedicated to a cure for cancer and the patients who enter, you begin to understand that to the community it is a gift given without expectation." **wcc**



Richard DiMarzo, Jonathan Friedberg, Alicia Coffin, and Paul Hanrahan



**"I believe in providence. It's not us who choose to become involved; it's something other than ourselves that involves us. You can call it whatever you like but I was meant to serve Wilmot and have Judy in the minds of others."** – *Richard DiMarzo*

# Voices

## Warrior Walk Honorees Put Voice to Cancer Survivorship

To celebrate the newly formed Clinical Cancer Survivorship Program at the Wilmot Cancer Center, organizers have planned a Warrior Walk for cancer survivors, which will be held Sunday, June 2, at the University of Rochester River Campus. The event coincides with the national celebration of Cancer Survivors' Day, and is designed to create greater awareness of the unique needs of those who have battled cancer, and to support a program formed to help them have a better and healthier future as they face ongoing health issues related to the late effects of their cancer treatment.

While the number of cancer survivors who have received treatment at the Wilmot

Cancer Center continues to climb rapidly, as do the national figures, this year's walk will highlight the stories of five individuals who have battled cancer or supported a loved one with cancer. Following are their stories, in their words:

### Emma Falk

Student at Our Lady of Mercy High School  
Hodgkin Lymphoma and Acute Myeloid  
Leukemia Survivor

I was diagnosed with Hodgkin lymphoma in July 2007, the summer before I entered the seventh grade. I was shocked and in disbelief to say the least. The news hit me

hard, but I knew I could beat it and would put it all behind me. I underwent three months of chemotherapy and was declared cancer free in late September 2007. In July 2011, I was diagnosed with Acute Myeloid Leukemia (AML). It was likely caused by the treatment I received for Hodgkin lymphoma. Words cannot quite describe how I felt when I heard this news, but I knew I could beat it just as I had the first time. I was hospitalized for a month at the Golisano Children's Hospital receiving chemotherapy treatments and went to The Boston Children's Hospital in August where I was hospitalized for over two months receiving chemotherapy, full body radiation,

**Mary**  
Schwid

**Leah**  
Shearer

**Scott**  
Kropman

**Emma**  
Falk

**Shannon**  
Case



and a bone marrow transplant (my sister, Aidan, was a perfect match). I remained in Boston for an additional month receiving outpatient care through the Dana Farber Cancer Institute.

The support of family, friends, and the community gave me strength. Without my family, I would not be here today. Through the toughest times, it is my family that gives me strength, courage, and motivation. I knew my family, friends, and the community, including people I have never met, were behind me and praying for me. Cards, social media, texts, calls, and posts on my CaringBridge website put a smile on my face and gave me the courage to fight on. Looking forward to the future and all the things I had always dreamed of doing with my life gave me motivation to fight every day.

These experiences have completely changed the way I look at each day. I realize that every day is a good day and have a new appreciation for every day and opportunity that I am given. I have learned to never take anything for granted. I have learned that with will and hard work you can achieve normalcy after overcoming the effects of treatments. Although I am not as physically strong as I once was, I am mentally stronger and I realize that my physical strength will come back in a matter of time and hard work. I realize what is truly important in life.

I want to be a part of the Warrior Walk because I want to show people that cancer IS beatable. I hope to be an example to all those that are battling cancer right now, will battle it in the future, and to their family and friends that will battle it with them. I am living proof. I am honored to share the day with so many survivors and family members that have had their loved ones affected by cancer. Their courage and strength is so important. I hope I can instill optimism in those battling cancer. Cancer is beatable.

The clinical cancer survivorship program will have a profound effect on cancer survivors. It will give survivors the connections, support, and opportunities needed to live a happy and healthy life after cancer. It will also give those fighting cancer additional motivation and optimism. It will be a support group for all those that have overcome the disease. For me personally, I am so excited to meet other survivors and learn their stories. I am interested in learning how to lead the healthiest life possible.

## Shannon Case

Non-Hodgkin and Hodgkin lymphoma Survivor

My name is Shannon Case, I have been married to my wife, Carrie, for 13 years and we have two beautiful children, Jamie and Luke, that are 4 1/2 years old. I work for a pharmaceutical wholesaler in the Rochester area as a System Network Analyst. My hobbies include cycling, reading, and computers.

My official diagnosis of Aggressive B-Cell Non-Hodgkin lymphoma did not occur until June 3, 2003. We had known about my cancer since April 2003. All I knew about cancer was what I had seen in the movie "Dying Young." I was terrified. I was afraid for my wife. I was afraid of the side effects of the chemotherapy and what it would do to me. Initially I was convinced that I was going to die. I drew a lot of strength from my wife. She kept motivating me and kept a positive attitude. She would encourage me and did not let me wallow in my fears. Praise and positive statements from family and friends helped a lot.

I was told I was in complete remission on November 25, 2003. We told everyone we could about the good news and enjoyed a very Happy Thanksgiving two days later. We waited until the summer to officially celebrate and took a trip to Disney for the first time.

After a routine CT scan on September 29, 2004 revealed a mass, I was told that I now had Hodgkin lymphoma. I wasn't afraid of the chemotherapy side effects this time. We were afraid it wouldn't work. We knew the chances of survival decrease when the cancer returns. We had asked at one point what the chances of survival were if the cancer returned and knew that it was around 20%.

Family and friends rallied together even more so this time around. They seemed more experienced the second time around and were able to anticipate what we needed. I also got a lot of inspiration from Lance Armstrong. He was just a regular guy (like me) and beat incredible odds to survive his cancer. I clung to that thinking he beat cancer why can't I?

On August 25, 2005 my oncologist (Dr. Friedberg) told us I was cancer free. We had a remission party that weekend (8/27) to celebrate the good news.

Many people do not realize that once the cancer is gone, it continues to be part of your life in some way. There have been ups

and downs. At first, there was joy at being cancer free, then there were periods of depression – all the support and attention suddenly dropped away. I had to find a new identity. I was a "cancer patient" for almost three years; my life revolved around that. Then all of a sudden, I was just this average guy. Staying with cycling helped to form a new identity – "healthy, alive guy." Staying active and eating healthy have continued to be part of my life and how I am raising my family. Health is much more important to me now than it used to be.

I feel it is vitally important to maintain a healthy lifestyle and stay positive. I would never have survived my cancer without the support of family and friends. These are the things I want to share with others who are battling cancer or helping someone who is battling cancer. Support, healthy living, and hope all are so important. The clinical cancer survivorship program can help survivors and those currently battling cancer to keep fighting. It can provide them and their caretakers with the support they need and teach them how to stay strong and healthy. Surviving cancer is not an individual feat; it requires a team, working together, each with a role in reaching the goal of survival. This program will improve the ability of the team members to provide what is necessary.

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**WARRIOR WALK | 2013**  
Celebrating Life Beyond Cancer

**Walk with us to celebrate the newly formed Clinical Cancer Survivorship Program at the Wilmot Cancer Center**

**Sunday, June 2**

**University of Rochester River Campus**

**For more information about the Warrior Walk, please go to: [warriorwalk.urmc.edu](http://warriorwalk.urmc.edu)**

**Coincides with the national celebration of Cancer Survivors' Day, and is designed to create greater awareness of the unique needs of those who have battled cancer.**

## Scott Kropman

Neuroendocrine Cancer Survivor

My family, which is my reason for living, consists of my wife, Stephany; sons, Skylar 16, Parker 14, Max 12, Cooper 10, Zane 4; and daughters: Chloé 7 and Logan 1-year, 7-months. My hobbies are coaching wrestling and football.

My initial response to being told I had cancer was actually not what most may think. I just called my wife and told her. She broke down and I said "it is what it is, let's just figure out how to beat it." I explained that she needed to remain positive and it will be okay. I have never really looked at it as a negative not sure why, I just never have. I still have that same attitude.

During my treatment, I drew strength from people, other cancer stories, etc. I don't know that I can even begin to explain how many people I would need to thank for the love and support I have received during this time – family, friends, the wrestling and football community, and my co-workers. My greatest strength comes from LOVE!! Not to mention I promised my doctor that I would get him into the medical journals by being the first neuroendocrine cancer patient to be cured – and I still plan on keeping that promise.

By participating in the Warrior Walk for cancer survivors I am hoping that I will help to educate the uneducated and bring light to a great program and clinic that will be available to help so many people in need of help. I feel the survivorship program will help to enlighten so many as well as allow for survivors, as well as those living with cancer, to have a place they can feel comfortable discussing and getting help they may otherwise not be able to obtain.

Changes are many but most notable. I do not sweat the small stuff and I have learned to "Live, Listen, Love, Laugh" and that "Love Will Prevail." I guess that I have learned to enjoy all the sweet little things that life has to offer and not worry about the annoying little things that are meaningless. I feel it is important that cancer is not a death sentence and in some cases (mine) is a new beginning. I have learned to look at the love and beauty in the world instead of the hate and pain. I have learned to slow down and enjoy the little things I used to miss. In short, I have become a happier, more patient, better person who truly understands unconditional LOVE.

## Leah Shearer

Program Coordinator,  
Teens Living With Cancer  
Thyroid Cancer Survivor  
Hodgkin lymphoma Survivor

I am originally from Lima, NY and have one younger sister and two wonderful parents. I am the program coordinator of the Teens Living with Cancer program (Melissa's Living Legacy). In my free time I love to travel, blog about my travels and experiences. I also enjoy theater and thanks to Patrick, the special man in my life, I am afforded the luxury of seeing it quite often.

The first time I was diagnosed, with thyroid cancer, it came as a shock and I had no way of understanding of how this eventually would truly change my life in a positive way. The second time I was diagnosed, this time with Hodgkin lymphoma, I truly had a deeper fear that perhaps I would not survive this ordeal. The second time was more of an unknown, as at the time I'd never met another cancer survivor who survived a second diagnosis.

During my treatment I was bolstered by support from my co-workers, friends and others in my community. I was lucky to feel supported and loved to summon courage for each step in the journey. Yet, it was the stories of young adult survivors that I sought the most to help me believe – the old adage strength in numbers.

I didn't consider myself truly cancer free until a year after my first diagnosis and I celebrated that with a party, commemorating the day with fun. The second celebration from my second remission was a trip to Europe which I used most of my savings to do, but it was vital to me moving forward – acknowledging that life is too short.

Since my diagnosis I've felt a deeper connection to other cancer survivors and a stronger resolve to use my life experiences as a way to help others. I've also had a renewed interest in keeping myself healthy, finding a way to exercise as often as I can.

The Warrior Walk is a great way to make a strong statement of the power we have together as survivors. Our stories are powerful and important to share because they can provide hope for others who face uncertainty. The new survivorship program will provide survivors with access to the kind of information that enables them to be informed about their treatment, connected to resources and vigilant about their follow-up care.

## Mary Schwid

Caregiver to husband, Steve, who died of soft tissue sarcoma

Steve and I met the summer after our sophomore year at the University of Wisconsin-Madison. He was from Milwaukee and I came from Chicago. We married and had our first child while in Madison, then in 1990 we moved to Rochester and Steve started his residency in neurology. I stopped working when we moved and became a stay-at-home mom. We had five children, four boys and a girl. After residency we wanted to stay in Rochester, and Steve became a professor at the University of Rochester, in the department of neurology. As a family we enjoyed boating, hiking, camping and playing games. We still enjoy boating, hiking and playing games, but camping was Steve's idea and I just went along. Camping is much better when there is a nice dry, warm, and critter-free hotel room involved.

Steve was diagnosed with soft tissue sarcoma in May of 2005. Initially my response was quite typical I think; there has to be some mistake. But as the week moved on it became quite clear there was no mistake, it was cancer and treatment began. My husband was a very pragmatic man, things happen and you handle them. This was the way he had always done things and continued till his death. Being his caregiver was in many ways a privilege, he trusted me. But it was also challenging because he often did not want help and clearly needed some.

It has been almost four and half years since Steve died. And I can say the kids and I are alright. We have a strong appreciation for each other and a perspective of what matters. We have learned that there are things you cannot control but you can get through them, and it's ok to keep moving forward with life when really sad things happen. We have learned that we can count on our family and that our friends are family. And most importantly, we have a different life but it's still a really good one. This is *something I would like all families to know.* [wcc](#)

# Wilmot Boasts Proud Legacy in Cancer Survivorship Research



RESEARCH

The number of people who have faced – and survived – a cancer is rapidly expanding. Yet, many will face a number of challenges throughout their lifetime as a consequence of their cancer treatment.

For decades, scientists at the Wilmot Cancer Center have been leaders in the study of the late effects of cancer treatment. From pioneering studies on radiation biology and the effects of exposure, to the groundbreaking work undertaken under the umbrella of URMCC's Cancer Control and Survivorship Program, Wilmot researchers have contributed important advances in helping patients and cancer survivors deal with troubling side effects of treatment. However, much remains to be done.

We are proud to have a robust research portfolio related to survivorship and to improving the quality of life of our patients. In this issue we highlight some of our more recent achievements and the many scientists involved. From a recently launched study on the long-term effects of platinum-based chemotherapeutic agents funded by the National Cancer Institute and a U.S. Department of Defense grant leading to new discoveries improving our ability to treat radiation injury, to studies that have identified ginger as an aid in easing nausea caused by chemotherapy, or a widely cited study on the very positive impact of yoga for survivors dealing with sleep disorders, we are leading the way.

We are also very excited that with the support of a generous donation the Wilmot Cancer Center has been able to initiate a clinical program addressing cancer survivorship, a logical progression from the world-class research that continues to be a hallmark of our center. As you know, the support of our community is essential to all that we do, both in the laboratory and at the bedside.

Thank you!

Sincerely,

Hartmut "Hucky" Land, Ph.D.

*Robert and Dorothy Markin Professor  
Director of Research & Co-Director  
James P. Wilmot Cancer Center*



Wilmot Cancer Center  
at Forefront of Survivorship Research

Survivorship researchers Lois B. Travis, M.D., Sc.D.,  
Jacqueline P. Williams, Ph.D., and Gary Morrow, Ph.D.



**D**oes the clock on survivorship start at diagnosis or five years later? Debate and various definitions among oncologists might be confusing, but one thing is crystal clear: Today, millions of cancer survivors are alive at all points in time, bringing a need for greater understanding of how to live well after cancer.

The Wilmot Cancer Center has a rich and deep history in research related to challenges faced by cancer survivors. For decades, Wilmot scientists have been studying the risks of second cancers, sleep disorders, nausea, and post-treatment decline of cognitive function. The notion of accepting responsibility for helping people cope with the physical and psychological effects of treatment, and improve quality of life, not just length of life, is part of the Wilmot Cancer Center tradition. The University of Rochester's long association with Philip Rubin, a pioneer in cancer radiation biology and cancer survivorship research, put Wilmot at the forefront — and outstanding research leaders such as Gary Morrow, Ph.D., Lois Travis, M.D., Sc.D., and Jacqueline Williams, Ph.D., are pushing a new, modern agenda.

Just as treatment is evolving, so are thoughts and ideas about survivorship. Instead of simply identifying and characterizing common and sometimes debilitating side effects of treatment, scientists are now looking for specific ways to lessen the side effects of chemo, radiation, and targeted therapy, and calculating who benefits the most and why.

They have already learned, for example, that fatigue and brain fog associated with cancer is very different from what most people feel when they skip a few good nights of sleep. And that exercise, once frowned upon out of concern that it was too taxing, might actually make some cancer patients feel better and perhaps do better.

In the future, risk estimates and prediction models will become the norm. Researchers and physicians will know why some people feel very sick during and after chemotherapy and others not as much.

They will continue to design effective interventions, and standardize them for many different situations. Emerging data will go a long way toward establishing research priorities, personalizing treatment, and using resources smarter, as the number of survivors is expected to reach 18 million people by 2020.

After all, survivorship research is really about how to thrive, not just survive.

### **CCOP Research Program a National Leader**

Over the span of a 36-year career, Gary Morrow, Ph.D., has made landmark contributions to research related to cancer survivorship and symptom management. As the head of Community Clinical Oncology Program (CCOP) at the Wilmot Cancer Center, Morrow has helped position the University of Rochester Medical Center and its multidisciplinary team of investigators at the forefront of cancer control research.

The CCOP program at URM is part of a national network of clinical research programs that develops, conducts, monitors, and evaluates clinical trials and trains researchers. Established in 1983, it was the first CCOP funded in a cancer center in the U.S.

Morrow's group includes a bevy of talented researchers who have contributed groundbreaking studies that have had national recognition and impact. Following is just a sampling of the recent studies conducted by CCOP researchers:

#### **The Positive Effects of Exercise:**

Exercise generally helps the nation's 12 million cancer survivors, and Karen Mustian, Ph.D., M.P.H. and her team are working toward being able to prove, with scientific certainty, that prescriptions for daily yoga or 20 minutes of walking will likely extend a patient's survival.

"In 15 years we've gone from being afraid to recommend exercise to people with cancer, to having enough data that shows, by and large, it is safe and effective, particularly for relief of treatment side effects," said Mustian, assistant professor

of Radiation Oncology at URM and an exercise psychologist specializing in cancer. "But when a patient walks in the door, he or she wants to know how to tailor exercise to their own situation. Should I bike, walk, or lift weights? Is there anything I should avoid? Can certain exercises lower my fatigue? And the scientific community has not settled into a place where we've developed explicit exercise prescriptions, or can effectively narrow the choices for patients."

Several URM studies suggest that knowing how to develop and apply specific exercise programs (dose and timing to achieve a certain outcome) is a realistic goal.

Mustian and Lisa K. Sprod, Ph.D., investigated physical activity among older people, a group they describe as often overlooked and underestimated in terms of their ability to live with cancer. Just last June, she and Mustian presented findings from two of their studies at the annual meeting of the American Society of Clinical Oncology (ASCO), in a session titled, *Staying Bold While Old*.

In another exercise-related study, Luke J. Peppone, Ph.D., a research assistant professor, investigated the effects of a yoga program on women with breast cancer who were taking aromatase inhibitors, medications that deplete estrogen and often cause severe menopause-like symptoms. A frequent complaint is joint pain and muscle aches, sometimes making it difficult for women to get out of bed or grip a fork and knife.

Peppone said a high percentage of breast cancer survivors discontinue aromatase inhibitor therapy because of side effects, putting them at greater risk for cancer recurrence. His study measured the self-reported quality of life and physical discomfort among 95 women taking aromatase inhibitors and 72 women who were not taking the drug. Each group took part in a four-week gentle yoga program. The women taking aromatase inhibitors reported a significant reduction in pain,

muscle aches, and total physical discomfort, Peppone said. The study will serve as a pilot to launch a larger study of exercise to relieve musculoskeletal pain.

In a controlled study of yoga therapy in middle-aged, mostly female cancer survivors showed that a four-week, customized gentle yoga plan significantly reduced perceived difficulty with memory. Michelle C. Janelins, Ph.D., research assistant professor at Wilmot, randomized patients to one of two groups: standard follow-up care after receiving adjuvant cancer treatment, and standard care plus a program that consisted of breathing exercises, gentle Hatha and restorative yoga postures, and meditation. The yoga group had significantly reduced memory difficulty compared to the standard care control group.

### **Controlling Nausea**

Nausea is a difficult condition to study, even though it is among the most common reported side effects of cancer medications. Since 1996 the CCOP group has investigated many aspects of nausea and contributed several significant findings to the practice of oncology. For example, Joseph Roscoe, Ph.D., a research associate professor at the James P. Wilmot Cancer Center has led studies that have shown that when patients expect to get nauseous, they often experience worse nausea than people who do not expect it. The expectation is usually associated with a person's prior experiences, such as a tendency to get motion sickness, or to become nauseous when pregnant.

Another study, presented at ASCO in 2009, concluded that people with cancer could reduce post-chemotherapy nausea by using ginger supplements, along with standard anti-vomiting drugs, before undergoing treatment.

Roscoe is now leading a team launching a large study across upstate New York, in a continuing quest to help cancer patients cope with nausea during chemotherapy by using relaxation techniques and acupressure wrist bands. An earlier clinical trial provided

the pilot data needed to secure a \$2.9 million grant, awarded by the National Center for Complementary and Alternative Medicine for the five-year project.

### **Studying and Reducing Side Effects of Treatment**

While the number of cancer survivors in the United States has tripled since 1971, gains in survival have come at the price of second malignancies and cardiovascular disease, according to a report by a national scientific committee chaired by URM's Lois B. Travis, M.D., Sc.D., and published in March 2012 in the *Journal of the National Cancer Institute*. Travis is internationally known as a leading long-term researcher in cancer survivorship, based on decades of groundbreaking work at the National Cancer Institute.

"For many survivors the successes of treatment have been offset by the late effects of cancer and its therapy," said Travis, a professor in the Department of Radiation Oncology and director of the Rubin Center for Cancer Survivorship at the James P. Wilmot Cancer Center at URM. "Although many complex factors influence the risk of second malignancies and other health issues after cancer treatment – including lifestyle choices such as diet, exercise, alcohol and tobacco use, as well as genetics, age, and immune system function – it is vital that we develop the best possible long-term risk estimates and prediction models, and that we establish research priorities and identify concrete ways to prevent serious additional health problems among cancer survivors."

The focus of the committee, which was assembled by the National Council on Radiation Protection and Measurement, was on the long-term consequences of radiation therapy, which is a cornerstone of cancer treatment and used in approximately 50 percent of all cancer cases. (Chemotherapy was addressed to a lesser degree, when used in combination with radiation.) In October 2012, a study led by Travis, as Principal Investigator, was awarded a



Barbara L. Asselin, M.D.,

\$5.8 million grant by the National Cancer Institute (NCI). The grant is funding a new, multi-center study of cancer survivors that could lead to ways to identify patients who are more susceptible to experiencing long-term and debilitating side effects from a common and effective chemotherapeutic agent.

Travis and her study collaborators at other U.S. cancer centers and an additional center in Canada will spend the next five years studying nearly 4,000 testicular cancer survivors who were treated with cisplatin-based chemotherapy. It has been estimated that a sizable proportion of patients treated with cisplatin-based chemo may experience hearing loss or constant ringing in the ears, another 30-40% sensory neuropathies (or nerve damage), and still others decreased kidney function. The objective of the researchers is to evaluate genetic susceptibility to long-term platinum toxicity. This study population is composed of testicular cancer survivors, most of them cured of cancer, and is considered ideal for examining the genetic underpinnings of long-term platinum toxicity given their typically young age at diagnosis, high cure rate, and possible lifelong risk of treatment side effects.

### **Protecting Hearts of Childhood Leukemia Survivors**

About 75 percent of children with leukemia who receive chemotherapy face life-threatening heart problems as they age, but an international study led by a University of Rochester Medical Center investigator shows that giving a cardio-protective drug during cancer treatment may prevent the damage.

Led by Barbara L. Asselin, M.D., professor of Pediatrics and Oncology at URM, the study was sponsored by the Children's Oncology Group and the National Cancer Institute. It is believed to be one of the largest trials to evaluate the effectiveness of the drug Zinecard (dexrazoxane), at protecting the heart during treatment of acute lymphoblastic leukemia.

"Today the majority of children with leukemia will be cured," Asselin said. "As our young people survive, though, we believe we will see many more cardiac issues. It is a problem that must be fixed because it is the leading cause of death later in life among these patients.

"We now have some very effective cancer treatments at our disposal but we really need to focus on promoting the good health of our survivors. Our care does not end with chemotherapy. Being there for many years into the future, and to help childhood survivors understand their risks, is so important."

### **Preventing Late Radiation-Induced Effects**

Improving our ability to prevent injury affecting healthy tissues of cancer patients treated with radiation therapy is a central research goal at the Wilmot Cancer Center led by Principal Investigator Jacqueline P. Williams, Ph.D., research professor in the Department of Radiation Oncology. A \$15 million, five-year award, received August 1, 2010, from the National Institutes of Health/National Institute of Allergy and Infectious Disease allows URM research teams to focus on testing the ability of known drugs and experimental agents –

particularly antibiotics, antioxidants, and anti-inflammatories – to ward off systemic radiation injury that affects the lungs, brain, skin, immune system and bone marrow.

"For decades we have built an expertise here in looking at the delayed effects of radiation exposure, mostly in the context of cancer treatment," Williams said. "The most exciting part of this project is that through these and other collaborative efforts, we believe we are at the brink of discovering ways to mitigate the damage caused by radiation and protect the body from the repercussions that can arise months or years after the exposure."

Cancer patients will benefit from this project, as researchers uncover new information about how to reduce side effects, such as a loss of brain function that can result from chemo and radiation therapy or how to protect blood vessels and bone marrow from radiation injury. The URM investigators will be working closely with industry partners to test emerging drugs in this area.

"Many of the known drugs and experimental agents that we are testing have the potential to reduce the side effects of cancer treatment without adding new toxicities," Williams said.

With a new clinical survivorship now in place at Wilmot and serving as a logical extension of their work, the energy of survivorship researchers is rekindled. With the creation of the clinical program, these researchers are poised for new discovery, and training the next generation of scientists. [wcc](#)



David Dougherty, M.D. and Patti Murray, RSN, M.S., associate director of clinical services at the Wilmot Cancer Center, display the award recently presented by the Greater Rochester Quality Council to the Wilmot Cancer Center Kaizen team.

## Wilmot Cancer Center Kaizen Team Recognized for Efforts with Quality Improvement in Patient Experience

The continuous improvement efforts of the Wilmot Cancer Center Kaizen team were once again recognized by a local organization. The team received a Silver Award in Team Excellence at the Greater Rochester Quality Council Showcase and Awards event, held in December.

This marks the second time in approximately a year that the Kaizen team has been honored for its efforts at examining and implementing ways to further improve the patient experience for Wilmot Cancer Center patients. They had previously been asked to present their work to the Greater Rochester Lean Consortium (GRLC), a cluster of organizations across the area which get together to share what they are doing with lean practices at their organizations and to learn from others how to apply quality principles and practices to improve their operations and deliver results.

The team's efforts have resulted in improvements in both patient satisfaction

and overall cancer center operations. By eliminating previously redundant check in and check out procedures within the clinic and infusion center, patient wait times have significantly decreased. Since the Kaizen exercise began in May 2011 mean patient satisfaction scores reached 93.0, the highest score in cancer center history. More importantly, the patient satisfaction scores have become far more consistent, indicating that the changes are not just short term gains but rather a reflection of long term staff commitment. The team was also successful in reducing costs as a result of eliminating waste and inefficiencies of the system.

GRQC is an affiliate of the Rochester Business Alliance, and its vision is to make Greater Rochester a national showplace for performance excellence. The organization is comprised of leaders from five sectors, including business, healthcare, government, education, and not-for-profit, and teaches performance improvement tools such as Lean Six Sigma, Malcolm Baldrige, and Quality for Leaders.

GRQC shares best practices and hosts site visits at member organizations. Lean Six Sigma black belt coaches work with teams on Rapid Cycle projects, resulting in efficiencies that enable not-for-profit agencies to provide additional service with the same or fewer resources. [wcc](#)



# Community Events Celebrate Spirit of Cancer Survivors, Judy's Fund

In conjunction with the Wilmot Cancer Center's newly launched clinical cancer survivorship program, staff members and supporters, including the leaders of *Judy's Fund: Hope for Cancer Survivors*, have planned some high-profile community events to raise the level of awareness of the needs of cancer survivors.

## WARRIOR WALK | 2013 Celebrating Life Beyond Cancer

### Inaugural "Warrior Walk: Celebrating Life Beyond Cancer" Helps Mark National Cancer Survivors Day

Make plans now to join Wilmot Cancer Center staff, supporters, and our growing number of cancer survivors Sunday, June 2, at the University of Rochester River Campus, for the center's first Warrior Walk. The event, designed to create greater awareness of the unique needs of those who have battled cancer, and to help them have a better and healthier future, coincides with the celebration of National Cancer Survivors Day.

The Warrior Walk will be a fun-filled event for cancer survivors to connect with one another and share in celebration with their friends, family and caregivers. Today, there are more than 12 million cancer survivors in the United States, a number that increases every day. These survivors deserve to have the fullest, healthiest possible life after their cancer care yet face many ongoing health challenges. The effects of cancer treatment can be far-reaching, and dependent upon many factors, including the type and progression of the disease, length of treatment, and the ever-evolving drugs and therapies used.

Through a very generous gift, Richard DiMarzo has established *Judy's Fund: Hope for Cancer Survivors*, which provides vital support for the new clinical cancer survivorship program at Wilmot. Through this program, cancer survivors will receive the support they need to successfully navigate the complex issues they will face throughout their lifetimes.

Go to [warriorwalk.urmc.edu](http://warriorwalk.urmc.edu) for information and to sign up.

All funds raised at the Warrior Walk will help support *Judy's Fund*, and contribute to:

- Development of care plans for specific cancers and treatments that are informed by cutting-edge research
- Funding educational visits for cancer survivors to review their care plans and treatment summaries (Most insurance providers do not cover these visits)

Educational initiatives in the region to help primary care providers gain information about how to best care for cancer survivors.

Participants have the option of participating in walks of varying distances, including 1, 5, 9 and 13.1 miles. An important feature, however, is that everyone walks the last mile together as a sign of unity and support for cancer survivors. Specific start times are as follows:

13.1 mile walk:	8:00am
13.1 mile fun run:	9:15am
9 mile walk:	9:15am
5 mile walk:	10:30am
1 mile walk:	12:00pm

After the walk, celebrate with other participants and enjoy food, live music, kid's games and education for cancer survivors.

Those interested can register as an individual or team online at [warriorwalk.urmc.edu](http://warriorwalk.urmc.edu), which includes the resources to create the team/individual fundraising page. The first 100 registrants will receive a free ticket to the Cancer Survivor's Night at the Red Wings game on Friday, May 17, 2013. All cancer survivors will receive a t-shirt to reflect how many years they have been cancer free.



### Leading off is a special partnership with the Rochester Red Wings - Cancer Survivors Night at the Ballpark - Friday, May 17, at Frontier Field.

A number of special activities will take place as the Red Wings take on the Durham Bulls, including a spectacular post-game fireworks show. For every ticket purchased through this promotion, \$2.00 will benefit the Wilmot Cancer Center. Companies or individuals purchasing 50 or more group tickets can also have a special message, or name of a loved one touched by cancer, displayed on the video board throughout the game and/or before the post game fireworks.

The Frontier Field gates open an hour before the 7:05 p.m., ballgame, and cancer survivors, their family and friends, and the community in general will have an opportunity to participate in some special festivities. Those include:

- A pre-game ceremonial walk of Cancer Survivors. Survivors are asked to wear white, and gather at 6:30 p.m. at the Sweetspot stand.

- Cheering on the Red Wings' mascot, Spikes, and some special guests as they get their feathers and hair shaved to recognize the spirit of cancer survivors

For more information, or to make a donation, contact:

Derek Swanson  
Rochester Red Wings  
(585) 454-1001, ext. 3036  
[dswanson@redwingsbaseball.com](mailto:dswanson@redwingsbaseball.com)  
OR

Katy Hanrahan  
*Judy's Fund: Hope for Cancer Survivors*  
[mkphan@rochester.rr.com](mailto:mkphan@rochester.rr.com)  
(585) 455-8591

## Wilmot Cancer Center Calendar of Community Events

### **Saturday, May 11 | Discovery Ball | Rochester Riverside Convention Center**

Join us for an evening of fun and celebration of the wonderful care provided at the Wilmot Cancer Center and the exciting research of Wilmot scientists.

### **Wednesday, May 15 | Dado Spring Fashion Show | Maxx at High Falls**

You won't want to miss this lively entertaining evening filled with the latest trends in fashion. For tickets stop in at Dado 2900 Monroe Ave. 14618 or call (585) 271-7890.

### **Friday, May 17 | Cancer Survivor's Night at the Red Wings Game | Frontier Field**

See page 19 for details

### **Sunday, June 2 | Warrior Walk: Celebrating Life Beyond Cancer | University of Rochester**

See page 19 for details

### **Sunday, June 9 | Steel Lillies 5k/walk | Webster Parks & Recreation Center**

Join family and friends of the late Tiffany Lill as they host the 2nd annual 5k/walk to support sarcoma cancer research. For more information visit [www.steellillies.org](http://www.steellillies.org)

### **Friday, June 21 - Sunday, June 23 | Brockport BBQ Fest | Northampton Park, Ogden**

Once again the Brockport Rotary will be sponsoring a BBQ and music festival for all ages. Part of the weekend's event will include a Kansas City sanctioned competition and a Kid's Q and Chili Cook-off. General admission is \$5, for more information visit [www.brockportbbqfest.com](http://www.brockportbbqfest.com)

### **Sunday, June 23 | 'For Pete's Sake' Golf Tournament | Victor Hills Golf Club**

Join family and friends of the late Pete Osterling as they support liver cancer research through their 2nd annual golf tournament. For more information visit [forpetessakememorial.com](http://forpetessakememorial.com)

### **Sunday, June 23 | KM Golf Tournament | Shadow Lake**

Once again family and friends of the late Kathleen Mrzywka will host a golf tournament to support brain tumor cancer research. For more information Email Bea Slizewski [beareads@gmail.com](mailto:beareads@gmail.com)



# Constellation Brands

Constellation Brands is familiar to many as the leading premium wine company in the world. What may not be as well known is their extraordinary philanthropy to a variety of charitable causes, ranging from cancer to sustainability. Health care is one of Constellation's core focus points, and the James P. Wilmot Cancer Center is fortunate to be a beneficiary of their extraordinary generosity.

Constellation recently supported the Wilmot Cancer Center's Breast Cancer Research Initiative. In November, Constellation hosted an event at their corporate headquarters inviting members of the group, interested individuals and their employees to attend. Constellation

## Corporate Partnership Spotlight: Constellation Brands

then announced that they would match donations made to this initiative up to \$25,000!

For many years, Constellation Brands has been underwriting the wine served at the Discovery Ball, Wilmot Cancer Center's biggest fundraiser. The funds raised to benefit cancer research are significantly increased because Constellation provides an important component of the evening's festivities at no cost to Wilmot. Constellation is also a Tasting Level sponsor for the annual "Toast to Your Health" wine auction, providing all of the wine for the event. In the past, Wilmot Cancer Center has been designated as the beneficiary.

"Constellation Brands is committed to making a positive impact on the communities where they live and work," said Ginny Clark, Constellation's vice-president of community affairs. What intrigues people the most is why we do what we do. It was the philosophy of Marvin Sands, the company's founder. He really felt that giving back in your own community, where your employees live and work really makes a difference. You can see the impact. It is something that Richard and Robert support and feel passionately about. When you know it's the right thing you do the right thing and they stand behind it."



## Moments of DISCOVERY

James P. Wilmot Cancer Center  
Discovery Ball

— Saturday, May 11 2013 —

Jeffrey and Patrice Pierce are the 2013 Discovery Ball Co-Chairs. A senior vice president at UBS Financial Services, Jeffrey has served on the James P. Wilmot Cancer Center Advisory Board since 2010. He is also a member of the Discovery Ball underwriting committee, and Patrice is co-chair of the culinary and decorating committee.

This year's Ball theme is "Moments of Discovery," a celebration of Wilmot's dynamic and collaborative team of physicians and scientists.

The couple was inspired to become more involved at Wilmot after a close friend passed away from cancer.

"As you know, the Discovery Ball is Wilmot's signature event and raises much-needed funds to support our commitment

to be a leader in world-class research, to offer comprehensive and compassionate care, and to provide access to some of the best and brightest minds in the field," the Pierces said. "Your support is essential to ensure that we remain at the forefront of new discoveries that benefit patients by preventing and detecting this deadly disease earlier, introducing new and less-invasive treatment, and ultimately save more lives."

**For tickets, sponsorship opportunities or more information please contact Shannon Martin at 276-4716 or [Shannon.martin@rochester.edu](mailto:Shannon.martin@rochester.edu)**

# Her Voice is Back, Stronger than Ever



**Georgiana Zicari** | Discovery Ball Inspiration Award Recipient

## *Moments of* **DISCOVERY**

James P. Wilmot Cancer Center  
Discovery Ball

— Saturday, May 11 2013 —

**G**eorgiana Zicari was just 15 years old when cancer was diagnosed the first time. She recalls being in complete shock and denial, wishing she didn't have to be different. She numbly followed the advice of her doctors and parents, enduring six months of chemotherapy and radiation, and then tried to move on.

It worked. For 14 years, she was cancer-free.

The second time it struck she was 29, dating her future husband, and having fun. It was a different cancer and a more complex treatment – but, happily, the outcome was the same: remission. In fact, her first set of clean scans came two months before her wedding day.

"We were ecstatic," Zicari said. "What a great way for my husband, John, and I, to kick off a new life together."

It's been five years, and Zicari's perspective has changed once again. Now that she's a mother herself with two children, she wonders how her own mother doled out so much optimism, strength, and love, while not revealing her personal fears. She's also grateful for John's presence; they met two months before the second diagnosis.

"He did not shy away, and has never left my side. Having lost his sister, Nancy, to breast cancer three years prior, I felt so badly that I was bringing this disease back

into his life," Zicari said. "It's amazing – this was one of the scariest times but also one of the brightest, having met him."

Zicari may credit others for being a constant source of inspiration, but at the Wilmot Cancer Center, she is the inspiring one.

As a teen she volunteered in the pediatric hematology clinic and at Camp Good Days and Special Times. Later, she participated in the Discovery Ball charitable donations committee, and on the Patient Family Advisory Council, co-chairing it in 2010.

She also assisted in creating a young adult cancer survivors support group at Wilmot, and coordinated three survivorship happy-hour fundraisers to benefit the Wilmot survivorship initiative.

"Childhood cancer survivors are a unique group," Zicari said. "We face many unique issues when we're robbed of our health. Ideally I'd like to see every pediatric oncology unit have a designated clinic for long-term survivors. I'm so pleased with what Wilmot is already doing in terms of a survivorship clinic – we are truly on the cutting edge."

Her journey began in 1991 with a lump on her neck. It was Hodgkin lymphoma. After treatment, doctors continue to follow her closely with imaging scans, blood work, and physicals. At the end of 2004, she

began to persistently lose her voice, and believed it was related to allergies. But doctors found swollen lymph nodes in her neck, biopsied them, and diagnosed thyroid cancer.

"After being cured for 14 years, a fear that I had pushed to the back of my mind came true. I did not live in worry about a recurrence; I was actually pretty shocked with this diagnosis. I was told the thyroid cancer was most likely a direct result of the radiation I received as a teenager," Zicari said. "I was angry, so angry. But eventually the truth I realized is: If I hadn't been treated with radiation, I wouldn't be here to fight the thyroid cancer. This has given me peace."

Her thyroid cancer was extensive and required a total thyroidectomy with lymph node removal. Surgery left her with a paralyzed left vocal cord, and she still struggles to project her voice in noisy places. Doctors also discovered her cancer had spread to the lungs. So Zicari decided on two years of aggressive therapy with radioactive iodine.

Since May of 2007, she said, all scans have been clear - although elevated tumor markers indicate a possibility of microscopic cancer cells in her system. She goes for a checkup every three months.

"I try not to let this consume me and just enjoy the wonderful life I have," Zicari said. "My faith is strong. I feel so blessed."

She also credits a close relationship with her physicians, including Louis "Sandy" Constine, M.D., professor of Radiation Oncology who treated her as a child, and Vaseem Chengazi, M.D., Ph.D., associate professor of Imaging Sciences, who was in charge of her radioactive iodine treatments. "We are so lucky to have thought-leaders right here in our backyard," Zicari said. "I was treated at Strong as a teen and I knew I would be treated at Wilmot for the thyroid cancer – no question in my mind."

**For tickets, sponsorship opportunities or more information please contact Shannon Martin at 276-4716 or [Shannon.martin@rochester.edu](mailto:Shannon.martin@rochester.edu)**



# Turning Loss into Legacy

**“YOU DON’T THINK** it could happen to one of your children. But Shirley, the oldest of our five daughters, died of breast cancer in her early thirties. Now we’re doing our part to find a cure and honor Shirley’s memory by giving to the James P. Wilmot Cancer Center at URM. For the sake of our daughters and grandchildren, our family made an estate commitment, and it’s part of the legacy we’re creating together. We’re also committed to supporting cancer research currently underway, and plan family time every year to make those decisions. You can’t put these choices off, because it could be too late. We feel good about making a meaningful impact now and in the future—together as a family.”

*—Henry Hansen pictured with wife Dorothy (center) and daughters Lana Reuss, Janet Felosky, and Sandy Alvarez (left to right). (Daughter not pictured: Darlene Shephard)*

**Imagine your legacy. Plan today to make it happen.**

To learn more about bequests or other planned giving methods,  
contact the Office of Trusts and Estates. (800) 635-4672 • (585) 275-7547  
[kreckel@alumni.rochester.edu](mailto:kreckel@alumni.rochester.edu) • [www.rochester.giftplans.org](http://www.rochester.giftplans.org)

All gifts count toward *The Meliora Challenge*, a University-wide fundraising Campaign that was launched in October 2011 and runs through June 30, 2016.





1

Many kids participated in the children's race.



2

Soccer players supported Blue September by hosting a car wash



## Thumbs Up

- \* The 5th annual "Road Rocks" event was held as a tailgate party for a Buffalo Bills game in memory of Rodney Stark, who was a big fan. Family and friends gathered to honor Rodney, and raised more than \$4,000 for Dr. Brasacchio's prostate cancer research.
  - \* Thank you to the 3rd annual MacKenzie-Childs special shopping day sale to benefit Wilmot. Shoppers that day helped raise more \$1,000 from a portion of their purchases.
  - \* The men's league at Blue Heron Hills golf club raised \$1,000 during a week-long fundraiser to support prostate cancer research at Wilmot.
- \* The Genesee Valley Conservation Club held its annual trap shoot event in memory of Ed Gordon. They raised more than \$500 for cancer research.
  - \* In celebration of breast cancer survivor and 2012 Inspiration Award honoree Megan MacKenzie's birthday, friends and family donated in her honor to support the Wilmot Cancer Center Breast Cancer Research Initiative. Together, they raised more than \$5,000.
  - \* The 5th annual Coop Cup golf tournament was held in memory of Clint Cooper. Friends and former classmates came together to raise in excess of \$9,000.
  - \* To celebrate reaching the one-year mark of being cancer free, Katie Rinallo hosted a Zumbathon fundraiser at the Downtown Fitness Club. The event raised \$600 for Wilmot.
  - \* Duke Energy employees hosted a golf tournament in honor of their late co-worker, Tom Spicer. The day's event raised \$500.
- 2 The Churchville-Chili varsity boys soccer team held fundraising events for Blue September, which marks prostate cancer awareness. They raised more than \$2,300 for prostate cancer research.
  - \* The 4th annual "Golden Challenge" soccer game between the Brockport and Nazareth women's soccer teams was another big success. The event raised more than \$1,400 to support the Comprehensive Breast Care Center at Wilmot.
  - \* For the 2nd year, Shear Emotion hosted a cupcake fundraiser for its patrons in Hilton to support breast cancer research. Donations amounted to more than \$450.
  - \* In recognition of Breast Cancer Awareness, the RIT campus ambulance crew created t-shirts and sold them to their members. They raised \$250 for breast cancer research.
  - \* The Honeoye Falls-Lima High School girls swimming and diving team recently went 'Pink' to support breast cancer research. Their event raised more than \$300.



Many groups came out to support pancreatic cancer research

- \* The University Health Service employees at the UR hosted a walk around campus in memory of their fellow co-worker Sam Ardillo. They raised more than \$250 to support the PEAK Lab for exercise programs for cancer patients and survivors.

**3** The 3rd annual "Step It Up" indoor walk attracted more than 1,000 participants to raise awareness and support for local pancreatic cancer research. The family themed event featured live music and activities and raised more than \$75,000 to support pancreatic cancer research at the Wilmot Cancer Center.

- \* To honor the life of Charles 'Jerry' Robinson, his colleagues from Central Western New York Girl's Basketball Officials held their first annual "Blow the Whistle on Cancer" basketball tournament. More than \$2,500 was raised to support pancreatic cancer research.



Employees of Davis-Ulmer supported Wilmot by wearing their favorite sports team jersey.

## Planting Seeds of Hope Event Shines Light on Community Support



Helene McMurray, PhD was interviewed by Evan Dawson about her research.

The Wilmot Cancer Center's first "Planting Seeds of Hope" fundraiser/awareness campaign was a huge success, raising funds that exceeded organizer's goals, and highlighting the outstanding support the greater Rochester community continues to lend the cancer center. The purpose of the event was to raise money for seed funding to support

research at the cancer center, and to raise the level of awareness throughout the region of the great things happening at Wilmot.

The event, staged in partnership with 13WHAM TV, featured live reports from the cancer center during 12 of 13WHAM's and partner CW16's newscasts throughout the day, beginning at 5:00 a.m. and continuing through the 6:00 broadcast. The interviews, by 13WHAM's Evan Dawson, focused on the work of Wilmot scientists and physicians, as well as the tremendous support provided by community organizations that raise funds for Wilmot.

Volunteers from faculty and staff at URMC, as well as community members from supportive organizations, manned the phones throughout the day to take pledges from viewers. The total raised over the phones was approximately \$31,500, exceeding the original goal of \$25,000. In addition, donations made through a staff dress down day brought in an additional \$3,800, making the total \$35,300 from donations from the community.

However, thanks to matching gifts provided by an anonymous donor and the Edelman-Gardner Foundation, the actual amount that will support seed grants doubled to \$70,600.

Special thanks to the local businesses who supported dress down day, including Alex and Ani, Hammer Packaging, Davis Ulmer, Connors Haas, Boylan Code and Cobblestone Capital Group and various departments in the University of Rochester. Thanks also to the dozens of volunteers who answered the phones and faculty/staff and community members who were interviewed during the day. The cancer center also extends a thank you to the West Winds Café for donating snacks, lunch and beverages throughout the day for the volunteers.



Many volunteers took pledges for the Planting the Seeds of Hope awareness campaign.

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TO LEARN MORE!**