



UNDERSTAND, PREVENT AND CURE CANCER  
**ONE MISSION**  
PATIENT NEWSLETTER

# Extraordinary \$4.2 Million Gift Will “Nurture the Heart and Soul” of RPCI Patients

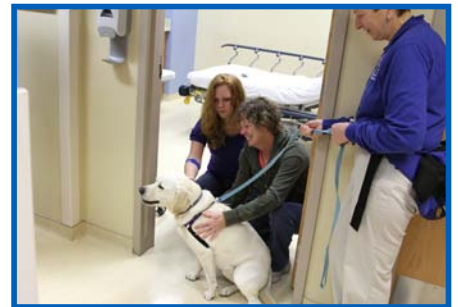
Ralph C. Wilson, Jr., founder of the Buffalo Bills football franchise, left a far-reaching legacy when he died in 2014 — not only for football fans across the country but also for cancer patients at Roswell Park Cancer Institute (RPCI). The Ralph C. Wilson, Jr. Foundation, created with a \$1.2 billion bequest from Wilson, has made the first of a series of generous gifts to the community with a \$4.2 million donation to RPCI. The funds will be used to establish the Ralph C. Wilson, Jr. Quality of Life Endowment at RPCI.

The endowment will enable new quality-of-life programs to get off the ground and provide the resources necessary for more patients to access those services. RPCI's current quality-of-life programs provide pastoral care, financial assistance to cover transportation and lodging for patients with financial need, wigs and hats for patients who lose their hair because of cancer treatments, the pet therapy program, and the Artists-in-Residence program, among other services.

Mary Wilson, Ralph C. Wilson's wife and a Foundation trustee, announced the gift Oct. 2 at RPCI. Hundreds of Roswell Park supporters — including staff, Buffalo Bills alumni, and even therapy dogs Sophie and Macie — attended the event.

“Roswell Park is not only one of the world's leading cancer research and care centers, but also an institute my husband cared deeply about,” Mary

An historic donation from the Ralph C. Wilson, Jr. Foundation will fund pet therapy, the Artists-in-Residence program, lodging and transportation assistance, and other RPCI programs aimed at improving quality of life for our patients.



Wilson said at the event. “Today's announcement is a continuation of the passion and dedication he showed for improving the quality of life for people and organizations in Western New York and across the country.”

“Many of our patients are going through one of the most difficult times of their lives as they battle this devastating disease,” said **Candace Johnson, PhD**, RPCI President and CEO and past chair of the Ralph Wilson Medical Research Foundation. “This incredible gift will allow us to provide a helping hand and extra support to help ease our patients' journeys as they face diagnosis, treatment, and recovery.”

Kim Bonafede, the parent of a pediatric cancer survivor, spoke at the event about the importance of the donation. “This journey has been incredibly difficult for our family, but because of the quality-of-life programs that Roswell Park provides, we've been able to gain some comfort and healing,” she said.

A panel commemorating the gift was unveiled at the announcement. Located in the main lobby, it features a photograph taken more than 25 years ago of Ralph C. Wilson, Jr. with a young patient, Nicholas Puleri. Puleri, who has been in remission for more than two decades, attended the announcement in October.

An inscription on the panel reads, “In treating the body, we must also remember to nurture the heart and soul of our patients.”



Mary Wilson, wife of the late Ralph C. Wilson, Jr. (left), at the unveiling of a commemorative panel in the lobby of the RPCI hospital, with RPCI President and CEO Candace Johnson, PhD (center), and Mary Owen, Ralph Wilson's niece and a trustee of the Ralph C. Wilson, Jr. Foundation.

# AROUND THE PARK



## You & Your Family Are Invited to the Tree of Hope Holiday Celebration!

Get ready for high spirits during RPCI's annual Tree of Hope celebration Friday, Dec. 11, from 4:30-6:30 p.m. in Kaminski Park (next to the hospital). You and your family are invited to enter a magical world of colorful dancing lights, live music, fun activities, delicious treats, and a visit with The Big Guy in the Red Suit. And there's more:

- Visitors can ride in a horse-drawn wagon festooned with bells.
- We'll raffle off whimsical gingerbread houses designed by RPCI staff, with proceeds supporting patient programs.
- A candle-lighting ceremony will honor cancer survivors and remember those who have passed away.
  - A very special RPCI pediatric patient will flip the switch to illuminate hundreds of lights on the Tree of Hope.



The event is free for Roswell Park patients and their families, but please **register by Monday, Dec. 7**, so we'll know you're coming. Register online at [www.roswellpark.org/treeofhope](http://www.roswellpark.org/treeofhope) or call 1-877-ASK-RPCI (1-877-275-7724).

You can park free of charge in the ramp at Elm and Carlton streets. And bundle up — activities take place outdoors.

While you're waiting for this year's celebration, you can enjoy the 2014 Tree of Hope all over again by watching the video at [www.RoswellPark.org/TreeOfHope](http://www.RoswellPark.org/TreeOfHope).

*One Mission* delivers news, information, and stories of hope and inspiration to the patients and families served by Roswell Park Cancer Institute (RPCI), in keeping with RPCI's mission to understand, prevent, and cure cancer. This patient newsletter is written, created and designed by RPCI's Department of Marketing, Planning, Public Affairs and Customer Relationship Management, with content contributed by various departments at RPCI.

## Questions? Suggestions?

• Email [RPCInews@roswellpark.org](mailto:RPCInews@roswellpark.org) or write to: Public Affairs Office, Roswell Park Cancer Institute, Elm & Carlton Streets, Buffalo, NY 14263.



## A Snowflake, a Wish, and a Sparkle of Hope

As you send out good wishes this holiday season, please add one more for our patients at Roswell Park. Every year we decorate the hospital with snowflakes that carry messages of encouragement for them. When you make a gift to our 2015 Holiday Fund Drive, you'll have a chance to share your own personal message on a snowflake. Your contribution will give our patients hope by providing financial support for research aimed at cures.

Please visit [giving.roswellpark.org/holiday](http://giving.roswellpark.org/holiday) to make a gift and send your message. Thank you for your kindness.

## Free Tile-Painting Class

Discover your hidden artistic talents Wednesday, Dec. 9, as RPCI Artist-in-Residence Barbara Murak leads a tile-painting program for patients and families. Free of charge, the event takes place from 10 a.m.-noon in the Resource Center for Patients and Families, inside the Sunflower Café. "Come and have fun and take home something wonderful!" says Barb. For more information, please call the Resource Center at 716-845-8659.

## Nominate an Extraordinary Nurse and Both of You May Be Off to San Antonio!

If you know an oncology nurse who provides exceptional care, here's your chance to give that person some well-deserved applause. CURE™ magazine invites you to nominate a special nurse for the 2016 Extraordinary Healer Award by writing a 700- to 1,000-word essay describing the nominee's compassion, expertise and helpfulness.

If your nurse is among the three finalists, both of you — plus one guest each — will be treated to a very special trip to attend a reception and award ceremony during the Oncology Nursing Society's 41st Annual Congress in San Antonio, Texas, from April 28-May 1, 2016.

Deadline is **December 15, 2015**. For complete rules, a nomination form, and additional information, please visit [www.curetoday.com/extraordinaryhealer](http://www.curetoday.com/extraordinaryhealer).



Roswell Park nurses: Kenneth Struck (left) and Rosita Brady (above)

## Send a Holiday Greeting with Extra Meaning This Year!

This holiday season, please support RPCI's quality-of-life programs by choosing cards and gifts from our Paint Box Project. Designed by our young cancer patients and their siblings, this year's Paint Box Project collection features 15 new designs, including Buffalo-themed artwork, cancer awareness ribbons, and Frosty the Snowman. The designs are also available on gifts, gift packaging, calendars, tableware and glassware. A portion of the proceeds supports patient-care programs at Roswell Park.

Visit [www.paintboxproject.com](http://www.paintboxproject.com) to explore the latest collection, which includes a holiday card variety pack. Some designs are also available in the hospital gift shop.



## Help Holiday Dreams Come True for Our Pediatric Patients

Cancer doesn't take a break for the holidays, but you can make the season brighter for our youngest patients.

Every December, Carly's Club at Roswell Park throws a party where Mr. and Mrs. Claus hand out presents to the children in our care. You can help Santa by donating a gift on the Carly's Club wish list. Please visit [giving.roswellpark.org/carlyswishlist](http://giving.roswellpark.org/carlyswishlist) to see the full list and learn how to make a pediatric cancer patient's dream come true.

# IMPORTANT NEWS ABOUT YOUR HEALTH COVERAGE



RPCI physical therapist Seiji Ohtake, with patient Marilyn Levy.

## It's Open Enrollment Time: Ensure Future Access to Care at Roswell Park

If you are currently covered by a Medicare Advantage Health Insurance Plan, or plan to be, you should know that not all plans have in-network access to Roswell Park. That's an important point to consider during the Medicare Open Enrollment period, which takes place now through **Dec. 7, 2015**. This is the time of year when you have the option of transferring to a different plan or sticking with the one you have, so it's important to know how each plan could affect your future health care choices.

### CHECK BEFORE YOU CHOOSE

If your current plan is not listed below among those that allow in-network care at RPCI, we urge you to select one that will give you unrestricted choice. Share this information with friends and family so they can be certain they'll have the option of choosing RPCI for their own treatment if the need arises in the future.

When selecting a health plan, make sure you review your benefit options carefully. Depending on the benefit plan, your copays and coinsurance options may come with very different out-of-pocket costs. If you are considering a health plan that is not listed as "in-network," please check the plan's provider directory or contact the insurer you are considering for more information. If you still have questions about your insurance, call a Roswell Park financial counselor at **716-845-4782**.

In-Network Health Plans	✓
Blue Cross Blue Shield (e.g., Senior Blue, Forever Blue, or PPO plan)	✓
Independent Health (e.g., IHA Encompass 65)	✓
Univera Healthcare (e.g., Univera Senior Choice)	✓
MVP (e.g., MVP Gold)	✓
Dual Policies - Medicare Advantage with Medicaid Secondary	✓
Traditional Medicare	✓
Traditional Medicare with Supplemental or Secondary Insurance (e.g., AARP, Empire, Medicaid)	✓

NOTE: Services are subject to each plan's pre-authorization requirements.

Out-of-Network Health Plans	✗
Aetna	✗
Emblem	✗
Fidelis	✗
Humana	✗
Today's Options	✗
United Healthcare (UHC)	✗
Wellcare	✗

NOTE: New patients to Roswell WILL REQUIRE a financial agreement specific to your treatment to receive care at Roswell Park if you are insured with one of the above out-of-network health plans. All services are subject to each plan's pre-authorization requirements. You may be subject to higher member cost share.

# PATIENT EDUCATION NOTES

## Creating Special Holiday Moments

Whether you are a caregiver or patient, the thought of holiday events and company may seem overwhelming. Cancer has stolen much of the normalcy from your life, and it is understandable if you are sad or angry that it now threatens your holidays. Some people pretend to feel upbeat to avoid ruining these traditions for their loved ones — but may wind up making it more stressful. Should you have the usual holiday festivities, cancel them, or find middle ground? How can you keep your favorite holiday traditions but let go of the pressure? Here are some tips.

- Talk with your loved ones. What aspects of the holiday are most important to each of you? Are there certain traditions you want to keep, and how do you feel about creating new ones? Be realistic about your energy level and adjust your expectations accordingly.
- Talk to your health care providers. Do you have any restrictions that must be considered (travel, food, or treatment schedules) when planning your holiday?
- If you can't share certain feelings with your loved ones, share them with someone else. Holding in your emotions will make the holidays more stressful. Crying can release tension, and laughter can make you feel better.
- Scale back. Continue a valued tradition on a smaller scale, with a shorter event, fewer people, or sharing tasks.
- Start new traditions. Instead of doing all the cooking yourself, have everyone bring a dish, use prepared foods, or go to a restaurant.
- Say no. Demands on time, energy, and finances increase around the holidays. Learn to say no politely and firmly, and refuse to feel guilty about it.
- Take care of yourself. Take a walk, eat your favorite nutritious foods, enjoy a bath or a nap — whatever it takes to relax and recharge. (Caregivers who get run down are likely to turn into patients.)
- Don't beat yourself up because you can't do what you used to. Distraction is underrated. Visit friends, indulge in a favorite hobby/activity, go to the movies, or snuggle up with a furry friend. Give yourself credit for the strength you've shown and for doing your best.
- If you are the organizer of a big group or family event, let go of the reins. Someone else can figure out where to seat 40 people and how to decorate. Use your energy to enjoy the occasion, share love, and create memories.
- Re-think gift-giving. Save time, energy, and hassle by ordering online or shopping from a catalog. If finances are tight, write to the people you love and remind them of the good times and laughs you've shared (maybe even an embarrassing moment or two). Tell them how much they mean to you.

**GOOD ADVICE FOR ALL OF US:  
KEEP YOUR HOLIDAY SIMPLE AND  
MEANINGFUL – AND DON'T OVERDO.**



Information on this page is provided by Roswell Park's Patient Education Department. Questions or comments? Please call **716-845-8784**.

# THE PATIENT EXPERIENCE

What's your story? If you have received a cancer diagnosis — whether it was yesterday or 50 years ago — RPCI's Pastoral Care Department invites you to take part in Life Recorded. The program gives you a chance to preserve your story for generations to come.

Life Recorded is a sister program of StoryCorps (heard on National Public Radio), an initiative that enables people to share their most meaningful life experiences through personal audio- or video-recorded interviews. Thanks to a generous donation from Philip H. Hubbell and a partnership with StoryCorps, we have brought the same idea to the Roswell Park community.

This fall we invite you to record your own story with a teenager — either a friend or family member — to help build connections between generations. You will be the storyteller, talking with this special person about the most important events in your life, tales from your childhood, events that shaped your values, reflections on what brings you joy, and — if you want to include them — thoughts about how cancer has affected your life.

You and the Life Recorded staff will decide when and where the recording will be made. You'll have the unique option of making either an audio or video recording, and you'll receive either a CD or DVD of the interview, free of charge. The recordings can be downloaded to a smartphone or uploaded to the archive at the American Folklife Center of the Library of Congress.

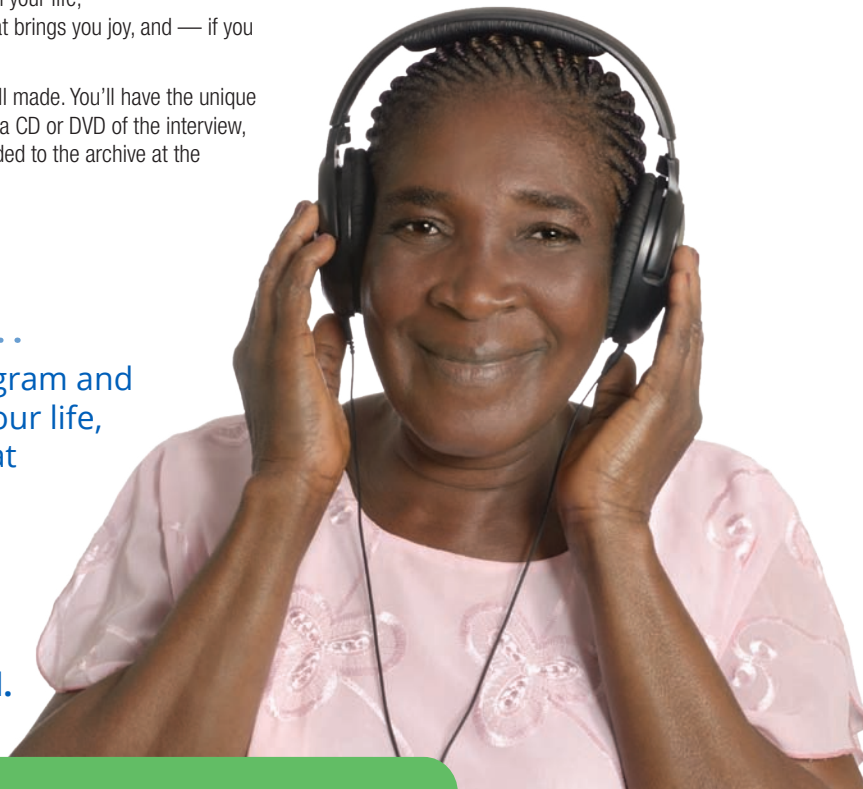
**LIFE RECORDED**  
A Project Inspired by **StoryCorps** Legacy

To learn more about the Life Recorded program and arranging a conversation with a teen in your life, please call the Pastoral Care office at **716-845-8051**.

Learn more at  
[RoswellPark.org/patients/treatment-services/supportive-services/life-recorded](https://RoswellPark.org/patients/treatment-services/supportive-services/life-recorded).

A VERY SPECIAL GIFT FROM

LIFE RECORDED



Clinical Trials 101 with Laurie Musial, MSN, BSN, RN

Assistant Vice President of Clinical Research Services



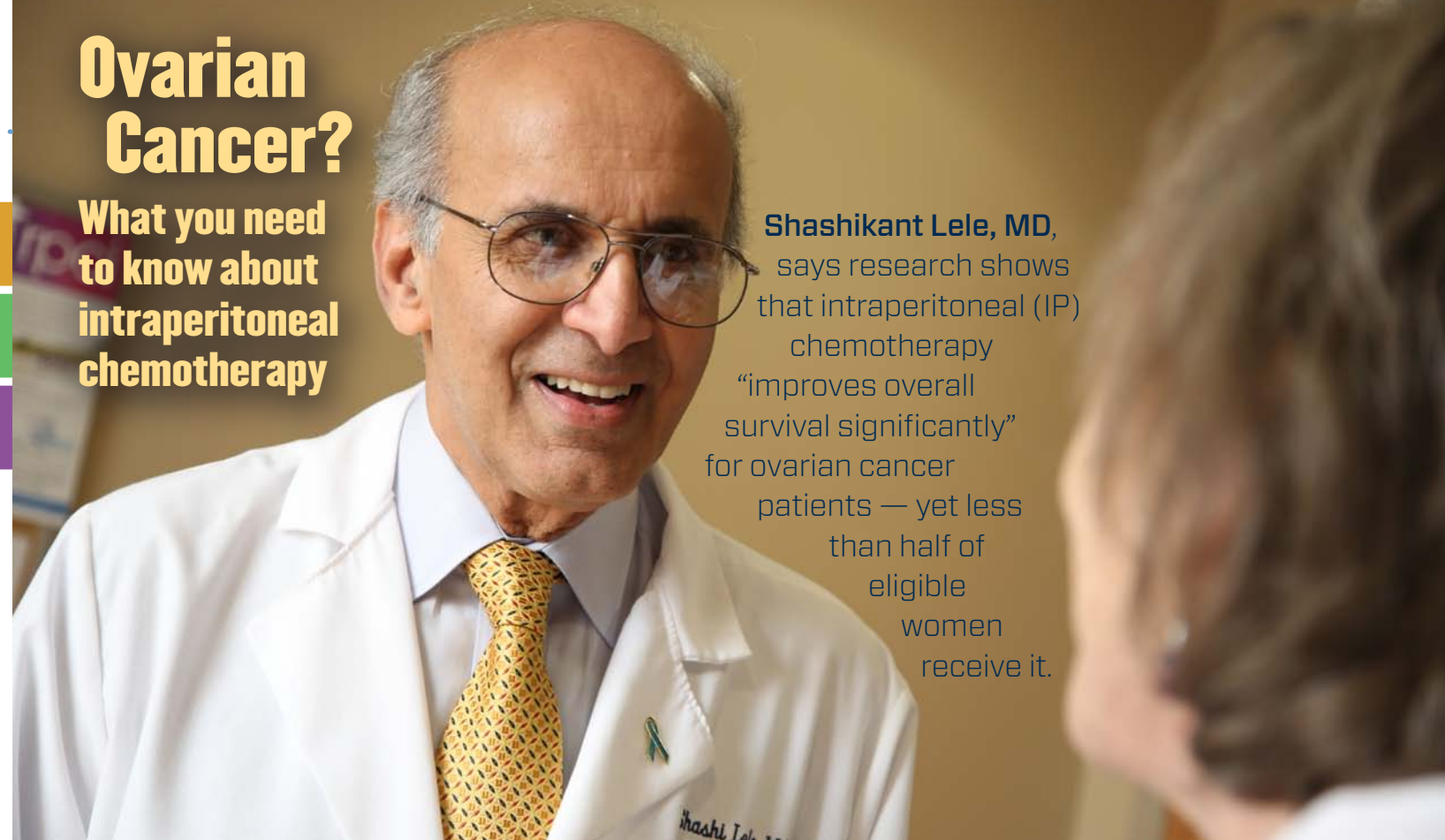
If you're a patient at Roswell Park, you may be offered the chance to participate in a clinical trial — also called a *clinical research study* — as part of your treatment plan. Clinical trials help researchers test new and promising methods of preventing, detecting, or treating a disease. Almost all of today's cancer therapies were evaluated in clinical trials before they were approved by the Food & Drug Administration (FDA).

Before patients can enroll in a clinical trial, researchers must provide institutional review boards and the FDA with evidence that the proposed treatment was found to be safe and effective in laboratory testing. The approval processes are very strict.

We make sure patients have all the information they need about the clinical trial they may be considering, and we encourage them to ask questions so they will be comfortable with the decisions they make about their treatment. We make sure the patient is well-informed about the expected outcomes and side effects and we make the effort to get to know the patient before they begin an investigational treatment.

## Ovarian Cancer?

What you need to know about intraperitoneal chemotherapy



**Shashikant Lele, MD**, says research shows that intraperitoneal (IP) chemotherapy “improves overall survival significantly” for ovarian cancer patients — yet less than half of eligible women receive it.

Delivering chemotherapy directly to the abdomen can significantly improve survival among women with ovarian cancer. The survival benefit is so great that nearly 10 years ago, the National Cancer Institute issued a special clinical announcement urging oncologists to use the treatment, called *intraperitoneal chemotherapy* (IP therapy). Unfortunately, many smaller hospitals and oncology practices still don't offer it. Even at larger centers, less than half of eligible women receive the treatment, according to a recent study in the *Journal of Clinical Oncology*.

Roswell Park's **Shashikant Lele, MD, FACOG**, clinical chief of Gynecologic Oncology and clinical chair of the Division of Surgical Subspecialties, uses IP therapy to treat patients with ovarian, fallopian tube, and primary peritoneal cancers. “It's the most effective way we have of delivering the chemotherapy to where the cancer is,” he says. “All Roswell Park patients with these cancers are considered for this therapy.”

Here, Dr. Lele answers some common questions about the treatment:

### WHAT IS IP THERAPY?

IP therapy delivers chemotherapy through a port in the abdomen, bathing the region in anticancer drugs to wipe out cancer cells that remain after surgery. Patients who have IP therapy typically receive it in addition to the usual intravenous (IV) chemotherapy. We use the same drugs for IP therapy as we do for IV chemotherapy.

### WHEN IS IP THERAPY USED?

IP therapy may benefit patients with ovarian or fallopian tube cancers that have spread, or patients with primary peritoneal cancer. These patients generally have advanced disease that has spread to the abdomen. First, the patient undergoes “debulking” surgery to remove all visible tumors. Typically there is a large tumor and sometimes hundreds of additional tiny tumors measuring from one millimeter to two or three centimeters in diameter throughout the abdomen. The surgeon painstakingly removes all visible cancer. Debulking surgery may involve removing parts of the spleen, bowel and stomach, too.

### HOW WELL DOES IT WORK?

Research shows that the therapy improves overall survival significantly: Most patients who receive IP therapy live 16 months longer than those who receive IV chemotherapy alone. The key factor is whether the patient's surgery is adequate. In the hands of gynecologic oncologists at RPCI, effective debulking is achieved in 80% of patients. In other facilities, where these surgeries are performed by general surgeons or gynecologists, only 40% are adequately debulked.

### WHICH PATIENTS ARE ELIGIBLE FOR IP THERAPY?

If a patient is able to undergo the type of surgery needed to extensively remove the tumors, that patient is eligible for IP therapy. However, various types of physical complications could exclude patients from this option.

### HOW IS IP THERAPY CONDUCTED?

Treatment involves six sessions in which the IP therapy is given at the same time as IV therapy. Patients are gently rolled back and forth to make sure the drugs are washed throughout the abdomen. Each session takes about three to four hours.

### WHAT SHOULD PATIENTS KNOW?

If ovarian cancer is suspected, patients should seek treatment from a cancer center where the gynecologic oncologists have experience with debulking surgery and intraperitoneal chemotherapy.

Read the study results in the *Journal of Clinical Oncology*:  
[jco.ascopubs.org/content/33/26/2841](https://jco.ascopubs.org/content/33/26/2841)



For straight talk from RPCI experts and survivors, visit our blog to read patient-focused news you can use about cancer detection, prevention, research and treatment. Read inspiring stories and learn about the latest therapies, tips for living with cancer and much more. **Visit RoswellPark.org/CancerTalk.**

Don't forget to sign up for our monthly e-newsletter that highlights our most popular posts from the CancerTalk blog. **Sign up at: RoswellPark.org/cancertalk/sign-up.**

NOVEMBER IS LUNG CANCER AWARENESS MONTH.

# Zeroing in on the Target: TEST DEVELOPED AT RPCI MATCHES GENETIC MUTATIONS TO SPECIFIC DRUGS

Sharon McCann, 54, was preparing for elective surgery when a CT scan picked up a spot on her lung. Testing at Roswell Park confirmed that McCann, who has never smoked, had stage 3B lung cancer. It had already spread to the lymph nodes in her chest, so surgery was not an option — and at that stage, the statistics are grim: only 5% of patients survive five years.

McCann underwent aggressive chemotherapy and radiation treatments. The cancer returned. She underwent more aggressive chemotherapy. The cancer returned again.

Then, in November of 2013, she learned about a new option. Her RPCI physician, **Alex A. Adjei, MD, PhD**, Chair of RPCI's Department of Medicine, Senior Vice President of Clinical Research, and The Katherine Anne Gioia Chair in Medicine, asked if she would like to be among the first patients to benefit from a new test developed at RPCI. OmniSeq Target™ matches patients to “targeted therapies” designed to shut down the specific gene mutations that allow their tumors to grow.

“Miraculously, I was blessed in two ways,” explains McCann. “The test found my mutation, which occurs in only 1% of lung cancer patients. Second, there was an oral targeted therapy, crizotinib (Xalkori™), that was effective against the mutation. I started on crizotinib on Christmas Eve of 2013.”

Eight weeks later, the tumor had shrunk to half its original size. It continued to shrink until “the last CT scans showed no sign of cancer,” she says. “Because it had spread to the lymph nodes in my chest, some cancer cells are probably still there, but they can't be seen on scans. There is no sign of metastatic cancer.”

**Jeffrey Conroy**, RPCI's Director of Genomics Consortium Technologies, says the test examines a patient's tumor sample for genetic alterations in 23 known



cancer-causing genes — including 15 associated with lung cancer — for which targeted therapies are available. Some of those therapies are FDA-approved; others are available through clinical trials. (Some of the 23 genes occur in more than one type of cancer, so the test can detect *actionable mutations* — those that can be treated with specific drugs — for melanoma, breast, and colorectal cancer as well.)

“Instead of having broad-based, standard chemotherapy treatments with an unpredictable response, we can say, ‘This is the targeted therapy for your specific gene alteration, and the responses are much stronger and last longer,’” says Conroy.

Since its introduction in August 2014, OmniSeq Target has been ordered for nearly 500 patients with late-stage non-small cell lung cancer, breast cancer, and melanoma, and there are plans to expand its use for other types of tumors.

McCann's next scans are scheduled for November 2015. “I pray it continues to be effective, and that this lasts a very long time,” she says. “I feel absolutely wonderful.”

THE NUMBER OF NON-SMOKERS WHO DEVELOP LUNG CANCER HAS BEEN RISING RAPIDLY IN THE U.S. SINCE 1990, AND RESEARCHERS AREN'T SURE WHY.

To learn more about OmniSeq Target and Sharon McCann's experience, visit Cancer Talk Blog at [www.RoswellPark.org](http://www.RoswellPark.org).

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Questions? Comments? Contact 1-877-ASK-RPCI or [askrpci@roswellpark.org](mailto:askrpci@roswellpark.org)