BY DEFINITION, the Alberta Cancer Foundation is a charity. But in the last few years, we have realized we are much more than that. Yes, we raised money as a charity does. And like a charity, we distributed that money across the province. But the real question we want to answer—and the one we hope you will ask us—is “So what?”

In this year’s annual report, we hope to answer that question for you. You will notice we are focused on “your investment” and “your return.” It might seem odd for a philanthropic organization to be using language found traditionally in the business world, but we think we owe it to you, our donors, to ensure you are getting the best return on your dollar. In cancer research, we think ROI stands for Results, Outcome and Impact—everything that directly improves patients’ lives.

No one invests without expecting a return on their money. In our case, that return is the biggest and most important one the human mind can imagine: healthy loved ones.

In the second half of the report, you’ll hear directly from patients, those Albertans who returned to their lives, their families and communities.

At the Alberta Cancer Foundation, we changed the way we do business. We do things differently than we have in the past and from other organizations. We move things along quicker, through a rigorous scientific review, collaboration and continued evaluation of your investments. We support innovation. We bring together donors, patients, health-care providers and researchers to unlock solutions that previously would have been unthinkable. We are a catalyst for change in the way we invest and deliver results.

We don’t just hope something good comes out of your investment. We make sure it does.

Think about what might happen if the Alberta Cancer Foundation wasn’t here to invest in certain programs. For example, without our donor dollars and strategic investment model, 6,000 Albertans would not have been able to take part in clinical trials over the past five years. More than 1,800 Albertans would have to worry about how to pay their mortgage or make financial ends meet, instead of being able to concentrate on healing—as your dollars allow them to do now.

This time next year, we may be able to say that we saved 100 people from dying of lung cancer, thanks to our investment into a provincial screening program we support. We want this list to go on and on.

Your return on investment is the most powerful one we can imagine: more lives saved from cancer. We share that same sense of urgency and know that if we don’t act on your philanthropic investment, we have a lot to lose.

We know we can do something about cancer. It’s time to be bold. Let’s close the gap. Faster.
Your Investment

Every day, we hear from donors who want to do something about cancer—make more progress, save more lives. We couldn’t do this without you. At the Alberta Cancer Foundation, we invest in big, transformative ideas that close the gap faster. Here is a sample of the investments we made on your behalf in the last year—investments that will detect cancer earlier, improve quality of life and provide better treatment options for Albertans facing cancer.

**Making It Personal**
$2 million over 5 years

Even though thousands of people receive the treatment every year, we can’t predict how patients will react to these therapies, and some treatments may not respond positively. The Cross Cancer Institute’s Dr. Ing Swie Goping, has identified a biomarker that could predict who should receive chemotherapy and who should not. Your investment will improve treatment success and the quality of life for Albertans facing breast cancer.

**Living A Better Life**
$1.9 million over 5 years

After treatment for head and neck cancer, swallowing difficulty can lead to dependence on tube feeding, affecting social interactions and overall quality of life. Research Dr. Rieger and her team at the Cross Cancer Institute’s Institute of Reconstructive Sciences, are evaluating a new drug that will transmit information from an adhesive pad under patients’ chins and instantly provide feedback to the team. This will allow Dr. D’ for detecting lymphoma tumours. In addition to these types of innovations, called personalized medicine, the drug is only given to people who will benefit from it and spares patients unnecessary treatment. As Dr. Bertheaume says, “It is a novel way to treat cancer patients.”

**Screening For Lung Cancer**
$3.5 million over 5 years

This year, nearly 2000 Albertans are expected to be diagnosed with lung cancer. Sadly, 1700 will die, yet no province has a lung cancer screening program. In an international study, one out of five lung cancer patients tested with a new no dose CT screening will be found to have a lung nodule, and of those, 90% will be diagnosed with cancer. For example, this facility contributed to the discovery of predictive biomarker for chemotherapeutic sensitivity in breast cancer, optimizing treatment. Today, this research is providing a new way to answer a variety of key questions that will allow for a better understanding of breast cancer.

**Translating Discovery**
$795,000 over 2 years

The Cell Imaging Facility at the Cross Cancer Institute is a flagship facility of the Alberta cancer community, changing the landscape of cancer research in the province. Your investment allows these teams to speed up the pace of knowledge that will translate to fewer cancer diagnoses or recurrences. Alberta scientists are considered pioneers in the study of physical activity and how it can be used to reduce the risk of developing cancer. Under the leadership of Dr. Christine Friedenreich, they have conducted the first studies of this, providing a new understanding of the role of lifestyle in cancer. Your investment allows these teams to learn more about the pace of knowledge that will translate to fewer cancer diagnoses or recurrences.

**Building A Better Model**
$145,000 over 2 years

One significant barrier the Alberta research community is facing is being unable to answer a variety of key questions that will allow for a better understanding of breast cancer. For example, this facility contributed to the discovery of predictive biomarker for chemotherapeutic sensitivity in breast cancer, optimizing treatment. Today, this research is providing a new way to answer a variety of key questions that will translate to fewer cancer diagnoses or recurrences. Alberta scientists are considered pioneers in the study of physical activity and how it can be used to reduce the risk of developing cancer. Under the leadership of Dr. Christine Friedenreich, they have conducted the first studies of this, providing a new understanding of the role of lifestyle in cancer. Your investment allows these teams to learn more about the pace of knowledge that will translate to fewer cancer diagnoses or recurrences.

**Reducing The Risk**
$392,000 over 2 years

There is a clear, unmet medical need for answers to how to reduce the incidence of breast cancer. The Alberta Cancer Foundation invests in a cross-disciplinary team led by Dr. Derrick Rancourt to develop a new personalized medicine therapy. Your investment allows these teams to speed up the pace of knowledge that will translate to fewer cancer diagnoses or recurrences. Alberta scientists are considered pioneers in the study of physical activity and how it can be used to reduce the risk of developing cancer. Under the leadership of Dr. Christine Friedenreich, they have conducted the first studies of this, providing a new understanding of the role of lifestyle in cancer. Your investment allows these teams to learn more about the pace of knowledge that will translate to fewer cancer diagnoses or recurrences.

**Easing The Financial Journey**
$700,000 each year

Some patients opt out of therapy if they can’t afford to take time off work. Or they will use savings to cover the cost of treatment. The Alberta Cancer Foundation’s Financial Assistance Program allows patients to focus on healing rather than worry about financial strain. Last year, our financial assistance program provided support to families 3,083 times. Thank you for making investments that matter.
My mother was diagnosed with colon cancer when she was 50, and she lived with it until she was 81. As a result of the multiple surgeries and radiation treatments, she had chronic digestion issues which ultimately led to her weakness and premature death. Unfortunately, my dad preceded her by a couple of years—he was diagnosed with multiple myeloma and it took him pretty quickly.

Having cancer in your body cannot be a pleasant experience, and then having to make your way through the health-care system on your own must only add to the stress and anxiety of the situation, which can’t be good for your overall health and outlook on life.

My parents had seven kids to turn to and help them through their illness. Being in Medicine Hat adds complexity especially when you also have to go to Calgary and maneuver between two different systems. As we traveled with our parents on their cancer journey, I kept thinking to myself, ‘how do people get through this experience if they don’t have the support that my parents had?’ I imagine many of them would rather not deal with it and just stay at home to die. That’s heartbreaking and that’s why the patient navigation program resonated with me.

When people are faced with a diagnosis, they inevitably have a lot of questions. Not only do they have a serious disease, but they often don’t know where to turn or who to ask. It’s comforting to think that cancer patients have someone they can talk to who knows the system and can provide support, comfort and answers. We all understand that our mental well-being has a significant impact on our health. Being able to reach out to a patient navigator just brings people peace of mind and that makes me and my family feel good.

This gift was made in memory of both my mom and my dad, Joan and Archie MacPhail. My wife, Kathy, and I, matched the donations made in their honour and we have had tremendous support from the community in both Calgary and Medicine Hat. One of my brothers-in-law was a big part of this initiative and was very generous with his support.

We understand that Shelley Burr, the nurse navigator in Medicine Hat has already seen over 200 patients in less than one year since it started—that’s a lot of people using the resource and seeking the support. With this said, we are pleased to be given the opportunity to support the navigator program in Medicine Hat and we’re looking forward to hearing more about the benefits of the program in the future.
We thought my husband, Allan, had an ulcer, but it turned out to be stomach cancer. We were devastated. He was given four months to live—he lasted two years, and his quality of life was very high right till the end.

In large part, I believe that was thanks to the wonderful care he received at the Tom Baker Cancer Centre and from our oncologist—Dr. Gwyn Bebb—a wonderful man who really listened to us. He understood, and respected, how Allan and I did everything as a team. The way he held Allan’s hand and looked him in the eye when he told him there was nothing more he could do. It meant so much.

After he died, I decided to give back to the Alberta Cancer Foundation for all of the wonderful care he received at the Tom Baker Cancer Centre. When I went to write my first cheque, I thought, ‘well, I could just send this in and be done with it,’ but instead I really wanted to talk to Allan. On every special occasion since—his birthday, our anniversary, Father’s Day, Christmas, the day of his passing—I take what I would have spent and donate it to the Foundation instead.

I’ve established a ritual that means as much to me, as I hope the money means to the Foundation. Allan was the love of my life. When we married, it was for forever. Even though I lost him to cancer in 2006, I still consider him to be my husband. Remembering him with a donation isn’t enough. So I don’t just write a cheque and mail it in. I sit at my desk to give from my heart and write to my heart at the same time. Here’s one of my recent notes:

“Happy birthday love—you’re 60! I remember your last milestone birthday, your 50th and the big party we had for you. This month is also our 29th anniversary! Marrying you was the best thing I’ve ever done. We had our ups and downs through the years, but we always faced whatever came our way as a team. As long as we had each other, we could handle anything.”

Sometimes, I want to tell him the latest family news. For instance, his 17th grandchild is on the way! I update him on how our daughters are doing, or how his son recently defended his master’s thesis. He would be so proud.

I make it a point to give where I can. It’s hard to say Allan loved a cancer centre, because no one wants to go there, but he really felt that way about the Tom Baker.

I will continue to do what I can to donate for as long as I can.
I like to call our organization a hidden gem. Many people didn’t know about us until we started promoting our charitable commitments a bit more—we’ve had a really good response from our employees and the community and have been able to help even more charities and organizations that need it.

The Edmonton Civic Employees Charitable Assistance Fund has been around since 1946 and now we’re up to almost 11,000 employees that contribute. Our employees donate one-quarter of one cent of their paycheque, which really adds up and allows us to make a real difference in our community. In fact, our last donation to the Alberta Cancer Foundation put us over the $1 million mark in total. To put this into perspective, since its inception, the ECECAF has donated more than $27 million to charitable organizations in the Edmonton region, more than $5 million in scholarships for members’ children and more than $600,000 towards special medical aid assistance for members and their families.

We have supported many Alberta Cancer Foundation projects over the years. Almost 15 years ago, tomotherapy was a revolutionary machine that allowed radiation to be delivered continuously, from all angles around the patient. It meant more accurate radiation treatment and left healthy tissue undamaged. Then it was the Linac-MR, led by the Cross Cancer Institute’s Dr. Gino Fallone, who put together two machines that the rest of the world said was impossible to do. Taking an image of a tumour and delivering radiation in real time is groundbreaking. Our most recent gift is for PET-MR, which is complementary to the other programs we’ve supported and will, in fact, evaluate the most important aspect of new radiation treatments—how to deliver the highest dose for cure, while minimizing damage to surrounding healthy tissue.

We were happy to be part of many of these projects from the beginning. We’ve heard from scientific leaders that our group helped launch these projects, that were in turn, able to leverage more investments at the local, provincial and national levels. Cancer is not a disease anyone wants and our whole vision is about impacting lives and promoting healthy communities. There is phenomenal work taking place right here at the Cross Cancer Institute in Edmonton, in the City of Champions, and it’s a great story to be part of.

Brenda Waluk
INVESTMENT: Linac-MR/PET-MR
As a friend, donor, former Cross Cancer Institute Rehabilitation Medicine employee and a cancer survivor, I feel honoured to be part of Fran Balmer’s estate gift.

Fran was a compassionate and big-hearted woman, who spent her whole life giving. She believed in doing things for others, and that way of thinking followed her after her passing in 2013, when she named the Alberta Cancer Foundation in her will.

While Fran made monthly donations to the Alberta Cancer Foundation in support of the Cross Cancer Institute, she wanted to leave an even more profound and impactful gift through a planned gift. As an occupational therapist for 35 years, Fran saw first-hand what people with physical issues go through. It was this experience, as well as seeing immediate family go through cancer, that inspired her to make a difference for Albertans facing this disease.

Fran’s outstanding gift to the Cross Cancer Institute touches every aspect of patient care by allowing the Alberta Cancer Foundation to fund things including televisions for patient rooms, specialty acute care beds, a harp program, lymphedema study and the head and neck program. These programs improve quality of life for cancer patients. I know Fran would be very pleased with that. Fran had a special connection with the Cross Cancer Institute. Her husband, John, was one of the carpenters that worked on the original building. And now, even after she is gone, she is improving the lives of patients at the Cross. Her ultimate goal was to make a significant difference for other people. And she is certainly doing that.”
The last six months have been crazy, to say the least. Since announcing I would be giving my $40 million lottery winnings to charity, I have received letters and phone calls from people all over the world asking me for help.

It was heart wrenching because they brought back too many memories. I feel bad because some of them were legitimate, but for me to qualify someone in Australia and decide if they should receive money was too hard.

The Alberta Cancer Foundation was the first place I knew I would donate to. My wife, Jan, died in February 2012 and I have such a soft spot for the Tom Baker Cancer Centre and am also interested in what is being planned with the new centre.

Cancer was such a big part of our lives for many years. Jan was first diagnosed with Stage 4 lung cancer in May 2006 and was told she had six to nine months to live. After chemo and radiation, we went back to her oncologist and they were all looking at the screen and said, “we have something to show you. The cancer on the lung is completely gone.” We were all happy and shocked at the same time.

She lived a very healthy life after that—a little spot on her other lung showed up a couple years after, but radiation took care of that. Then in October 2012, the day before we had our annual trip to Phoenix planned with friends from Regina, she told me she had a really bad migraine and needed to be in a quiet, dark room. I took her to the hospital to be safe, rather than have to worry about something going wrong on our trip to Phoenix. They found a tumour in her brain.

The brain is such a delicate thing. Doctors had to go through one inch of brain mass to get at the tumour and it caused a stroke. So for the next five months of her life, she was in and out of the hospital, until she finally passed away.

Jan was a wonderful mom, grandma, wife and a good friend to all. She beat the odds for six years and we, including her oncologist, truly believe it was because she had such a positive attitude. She was one of a kind and just an incredible human being.

She would be happy with what we’re doing. I’ve already received thank you letters from people who benefitted from the Alberta Cancer Foundation’s patient financial assistance program and it’s heartwarming. I had my own plans to do something with my money before I won the lottery and this has allowed me to do bigger and grander things. It is such a good feeling.
REAL RETURNS FOR ALBERTANS
WE HAVE LOFTY GOALS for our cancer program in Alberta. We believe our program can be among the best in the world, built on evidence-based research that drives improved patient outcomes. It's a bold vision, but with your continued support, we know we can deliver.

We know that for the health system to work well, it must be patient-driven and patient-focused. We must put the interests of the patient at the centre of everything we do. We also know that we must work hand-in-hand with partners like the Alberta Cancer Foundation, to ensure we can quickly and effectively accelerate research discoveries to the clinic, with the ultimate goal of enhancing patient care and improving Albertans' lives.

Together, we can deliver the return on investment that is so important to all of us and our loved ones: more birthdays celebrated, more years together and more moments shared.

Research discoveries offer hope to patients and families. In turn, we need to implement these discoveries into how we provide care better and faster, improving outcomes for Albertans.

Thanks to you, we are developing innovative solutions that are vital to translating research into life-saving therapies. We have to look beyond traditional ways of thinking to find those big, transformative ideas to ensure we can prevent more cancer, diagnose others at earlier stages, improve access to treatment, and truly create patient-centred care.

Investing in prevention, screening, research and care in Alberta is investing in our future. We must make it a priority.

Message from Dr Paul Grundy

CHIEF PROGRAM OFFICER & SENIOR MEDICAL DIRECTOR CANCERCONTROL ALBERTA

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As you will read in this “return” side of the annual report, Albertans are benefiting from the bright minds and compassionate care we provide in CancerControl Alberta, but we know there is much more we can do. With your continued support, we will be able to offer you and your loved ones the best possible treatment and care available—anywhere.

Together, we can make a difference. By investing in a better future for cancer care in Alberta, we will all reap huge returns.

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AT THE ALBERTA CANCER FOUNDATION

We are focused on changing the lives of Albertans facing cancer every day. Every year, we are busy making the important investments that translate into providing hope and healing, while improving and advancing the care of Albertans.
In 2007, I found a lump on the right side of my jaw. I had chemotherapy and radiation and 75 per cent of my tongue removed. I was fine for six years and then found another lump. This time it was on the other side of my face. I had the same surgery as the first time, but they had to remove 100 per cent of my tongue.

Doctors had to take grafts of skin from my wrist and thigh to try reconstruct parts of my tongue and jaw. I had to re-learn everything, to speak, to swallow. It’s been really hard. I am now one-year post-swallowing therapy and it’s been really beneficial. It’s helped with things most people take for granted.

If I want to swallow a sip of water, for instance, I have to concentrate on what I’m doing. I have to think: swallow... swallow... swallow... Then hold my breath. Clear my throat. That’s my routine for one sip of water. If I am distracted in a group of people, I can choke. Sometimes it’s easier to just not do anything in a group. Often, I just stay home and that’s hard.

Therapy has made a difference. It’s hard work, but if you take it seriously, it pays off. When you think about what you’re doing, it becomes second nature after a while. But still, I only drink water right now. I am waiting on a dental procedure and am trying to avoid any infection within my mouth from any form of food. I get my other nutrition through a peg tube in my stomach, which I’ve had since 2007. I do have smoothies, only not orally—I just tube feed them.

Sometimes I miss eating food, especially if I smell something delicious, but I can’t dwell on it. My husband is on the road a lot for work, but when he comes home on the weekend, I still cook for him because it gives him pleasure. I can’t taste it to see if it’s ok, but it makes me happy and it makes him happy. My husband is so fabulous, he’s been my rock.

It’s been a hard road, but I’m happy to hear about research for head and neck cancer patients—it’s important to try to get some of your life back. Therapy helps, particularly swallowing therapy. It makes me happy to know that even more Albertans will have access to this much-needed resource.
Four and a half years ago, I had a normal life. I was married to a wonderful man. I had a career that I loved, and many friends. But in December of 2009, I heard the three words that change everything: “You have cancer.”

I was diagnosed with stage IV breast cancer. My husband Pat and I learned that it had already spread to my lymph, liver, lungs and bones.

PAT: Everything happened so quickly. One moment we are hearing that fateful diagnosis, and the next we had palliative care in our house talking to Jenn, making at-home care arrangements. The moment I saw them in our house, my knees buckled. The reality of the situation sunk in, and it was unbearable.

Jenn: About a week after the diagnosis, I began aggressive chemotherapy at the Tom Baker Cancer Centre. To say that my first rounds were difficult would be an understatement.

After five and a half months of chemotherapy, as well as a double mastectomy, I learned the cancer had spread to my brain.

Until recently, I was undergoing daily chemotherapy and facing possible brain surgery, but fortunately I was able to start a new chemotherapy treatment recently approved in Alberta. TDM-1 is a ‘smart’ drug that’s able to penetrate the blood brain barrier and specifically target cancer cells while leaving healthy cells alone.

PAT: Now she only needs to be at the hospital once every three weeks. They say she is a medical miracle, but we know she’s alive thanks to research breakthroughs. We wanted to be a part of that. We want to support the research that will push us further than ever before. We need to arm the proper teams with the right tools so they can answer questions about cancer.

Creating the Pink Cup Charity Classic golf tournament was our way of “paying it forward.” There aren’t enough adjectives to describe the doctors, nurses and staff at the Tom Baker—there isn’t one person who hasn’t made an impact or brightened our lives.

Jenn: It’s been humbling to see friends, family and people I have never even met step into my life and offer support; to see how Albertans come together to support research so that cancer patients can receive the newest and most effective treatment options. People don’t realize what it means. I am so thankful.

Jenn Birchall
& Pat Murray

Return Story

They say she is a medical miracle, but we know she’s alive thanks to research breakthroughs.

RETURN:

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Stella Hernandez

I was born in Colombia, and moved to Edmonton almost seven years ago. I came to Canada with the dream of building a better life for my family. But it was not easy.

In Colombia, I was a civil engineer for 15 years. But because of the language barrier, finding a similar job in Edmonton was difficult. It was also during this time that my husband of 24 years decided we should separate. I was blindsided. I felt like my life was falling apart.

I did find a junior entry-level position at a technological company. At the beginning it was very difficult for me, but I was committed to making this new opportunity work.

I was laid off after a month. I took language courses and upgraded other skills, but still, no employers called back. Desperate, I decided to take a job as a housekeeping attendant. I worked full-time, but without benefits.

It was during this time, I noticed bruises on my legs, and that my gums were swollen. I went to the doctor, and was prescribed antibiotics. But things only got worse. Concerned, I went back to the doctor and was sent for a test. Later that night I received a phone call that my results were in. I had cancer.

I couldn’t believe it. My sons were devastated. I immediately had a biopsy, and was diagnosed with Acute Myeloid Leukemia, an aggressive form of Leukemia. At the end of the first stage of treatment I was told I needed a bone marrow transplant in Calgary at the Tom Baker Cancer Centre. My brother in Colombia ended up being a match. I took what little savings I had, and paid for him to come to Calgary.

Following surgery, I spent 23 days in the hospital. Once I was cleared, my social worker at the Tom Baker, Holly Minor, helped arrange for me to live in an apartment with my two sons and brother. It was also during this time Holly arranged for me to receive financial help through the Alberta Cancer Foundation’s Patient Financial Assistance Program. I am so thankful for Holly and the Alberta Cancer Foundation’s Patient Financial Assistance Program. Because of the financial aid I received, I was able to go through treatment without having to worry about money. I could focus on healing, and getting better for my sons.

Four months later, I was declared cancer-free. Helping others is a reflection of love towards other people. I will be forever grateful for the peace of mind.

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I did find a junior entry-level position at a technological company. At the beginning it was very difficult for me, but I was committed to making this new opportunity work.

I was laid off after a month. I took language courses and upgraded other skills, but still, no employers called back. Desperate, I decided to take a job as a housekeeping attendant. I worked full-time, but without benefits.

It was during this time, I noticed bruises on my legs, and that my gums were swollen. I went to the doctor, and was prescribed antibiotics. But things only got worse. Concerned, I went back to the doctor and was sent for a test. Later that night I received a phone call that my results were in. I had cancer.

I couldn’t believe it. My sons were devastated. I immediately had a biopsy, and was diagnosed with Acute Myeloid Leukemia, an aggressive form of Leukemia. At the end of the first stage of treatment I was told I needed a bone marrow transplant in Calgary at the Tom Baker Cancer Centre. My brother in Colombia ended up being a match. I took what little savings I had, and paid for him to come to Calgary.

Following surgery, I spent 23 days in the hospital. Once I was cleared, my social worker at the Tom Baker, Holly Minor, helped arrange for me to live in an apartment with my two sons and brother. It was also during this time Holly arranged for me to receive financial help through the Alberta Cancer Foundation’s Patient Financial Assistance Program. I am so thankful for Holly and the Alberta Cancer Foundation’s Patient Financial Assistance Program. Because of the financial aid I received, I was able to go through treatment without having to worry about money. I could focus on healing, and getting better for my sons.

Four months later, I was declared cancer-free. Helping others is a reflection of love towards other people. I will be forever grateful for the peace of mind.
When I was first diagnosed with colon cancer 10 years ago, my family and I had to navigate through treatment on our own. The second time I was diagnosed with cancer, my wife and I did it solo again.

By the time I was diagnosed with cancer for the fourth time, the Alberta Cancer Foundation’s Patient Navigator was in place at the Margery E. Yuill Cancer Centre in Medicine Hat, and I can honestly say, it has made all the difference. Going through a cancer diagnosis can be confusing enough as it is. It is on your mind 24 hours a day. It is not something that goes away. Going through it without knowing who to turn to for answers, is downright stressful.

You see, living in Medicine Hat and having to go through chemotherapy and deal with travelling to the Tom Baker Cancer Centre for surgery and tests, things can get confusing. Shelley, my patient navigator has been a godsend—every time I talk to her, I breathe a huge sigh of relief, she lifts the burden off my shoulders, so I can focus on healing.

When I was going through my cancer journey for my colon cancer, lung and even my first liver cancer diagnosis, I had no one to turn to with my questions or concerns. There was no one who you could quickly call to help with travel or treatment concerns. You just did it alone.

Now, all I have to do is call Shelley and she is on it. She will find out everything I need to know, whether that is helping to arrange travel, schedules, or helping with paperwork. She walks me through my diagnosis and prognosis, and empowers me to make informed decisions.

I can’t imagine doing this without her now.

When Shelley first became my patient navigator in February of 2013, she organized a gathering with speakers who have already had cancer or were still going through treatment. I can’t even begin to describe what this did for my wife and me. Not only did it bring a level of ease, but it felt like everything was going to be okay. And I didn’t have that feeling before.

Having Shelley in my corner lets me focus on the things I love: family, friends, and my hobbies. Since I’ve retired, I love spending time in my garage fixing things for my kids, and woodworking—it’s my time and space to unwind from everything.

I’m so thankful to have Shelley navigating me through this journey, she feels like family, and I couldn’t have picked a better person for the role.
I was diagnosed seven years ago with chronic lymphocytic leukemia. If you can get through the first five to seven years without your blood test numbers “getting stupid,” you’re probably good for decades.

At five and a half years, my numbers’ IQs sank, so my hematologist, Dr. Walter Blahey, hunted down a promising clinical trial for me. I started it last fall but was placed in the control group, which meant I received the standard drug, chlorambucil, instead of the newer one they were testing. I started it to be of “no clinical value,” to use my doctor’s words.

It was a challenging winter and I didn’t even realize it at the time. You just accommodate and adjust and make do, but looking back now, it was a terrible time. Getting out of bed, staggering to my ‘fainting couch,’ or washing the odd dish was sometimes it for the day. But the second arm of the study meant that, when my numbers got bad enough again, I could receive the newer drug, ibrutinib. This drug interferes with cancer cells and prevents them from replicating.

I didn’t have any expectations. But, three weeks in, I would do a task and then think, ‘I’d better sit down,’ and I realized I didn’t have to. So I’d do another task. And another. Soon I was doing stuff around the house, gardening, talking to people, walking to the store. It dawned on me that this drug might possibly be making quite the difference. Four weeks after I started, we tested my blood and my numbers were glorious! Four weeks after that, they were even better. It’s been absolutely astonishing.

I have a clinical nurse named Anna Giulione and I have built a small shrine in my heart for her. She fought hard to get me on ibrutinib. My lymph nodes were so swollen I looked like Winston Churchill’s bulldog on steroids and she knew I was really, really sick. Now I’ve had more life in the last two months than in the last 10 years. It’s an amazing treatment.

The impetus for me to take part in this clinical trial was to have a life, but I am also aware that you don’t get anywhere with new meds unless somebody tests them—especially with cancer. Science is just getting its head around things and there is still much to learn. Being part of the trial is important and I recognize that it is helping answer questions not only for myself but for others. The faster everyone else finds out about this, the better. Who wouldn’t want to see their life returned to them, as I have? My husband, son, friends and I are so grateful—we’re still doing our happy dance.

Sharon Neufeld