

MELANOMA

THROUGH MY LENS REFLECTION

PROJECT





This project results from a collaboration between Save Your Skin Foundation and
Novartis Pharmaceuticals Canada Inc.

NPR/TAF/0021E

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FOREWORD FROM

KATHY BARNARD

THE SAVE YOUR SKIN FOUNDATION



My journey started in 2003 when I was diagnosed with stage IV malignant melanoma. I never dreamed melanoma could be something I could die from. From the moment I heard the word “cancer” my family and I began our search for information or support to help alleviate our fears and anxiety. When we came up with nothing, the uncertainty we were living with intensified.

Then in 2005 my world shattered when I learned the cancer had spread to my organs. I was told that I had six months to live. My family and I felt desperately alone and lost. While I battled this disease I knew that something had to be done for all the other Canadians living with advanced melanoma, who were also fighting for their lives, but felt lost and alone. In 2006 my family and I took action and created the Save Your Skin Foundation, a place where advanced melanoma patients could go for information, hope and support.

This year marks the 10-year anniversary of the Save Your Skin Foundation and 10 years since I was told that I had six months to live, so I wanted to do something special. I wanted to capture the melanoma patient’s journey in a unique way: The emotions, the thoughts, the moments of despair and the moments of hope. As the saying goes, “a picture is worth a thousand words.” This is why we created the Melanoma Through My Lens Reflection Project. Six Canadians including myself, living with advanced melanoma, have come together to tell our melanoma stories in a visually impactful way.

This book captures our individual journeys in a series of photos that tell our own personal stories with one common message: We are not alone and neither are you. We have come together to raise awareness and to make a difference. By sharing this e-book with as many people as you know, you can help spread the word.

KATHY BARNARD,
Founder and President of the Save Your Skin Foundation





MY HAPPY PLACE

"During MRIs and CT scans, my eyes are closed and I am on my beach, hearing the surf pounding and birds chirping. From the day I was diagnosed, the beach was my place of solitude and it remains that way today. Even on grey days when I feel fear and uncertainty, I see some blue sky, and I see hope."



MELANOMA DOESN'T DISCRIMINATE

"Like no two rocks on the beach are the same, no melanoma journey is the same, and anyone can be impacted. But you are not alone. The beach is made up of a lot of rocks, and no matter how different they are they all come together."



WHAT'S IN THE EAGLE'S MOUTH?

"My nephew and I saw this eagle. We wondered what it had in its mouth and saw it had a stick. It was going off to build something. Not only did this resonate with me because it reminded me of building the Foundation, it just made me feel good. It made me feel hopeful, peaceful, compared to the fear I felt when I was first diagnosed."



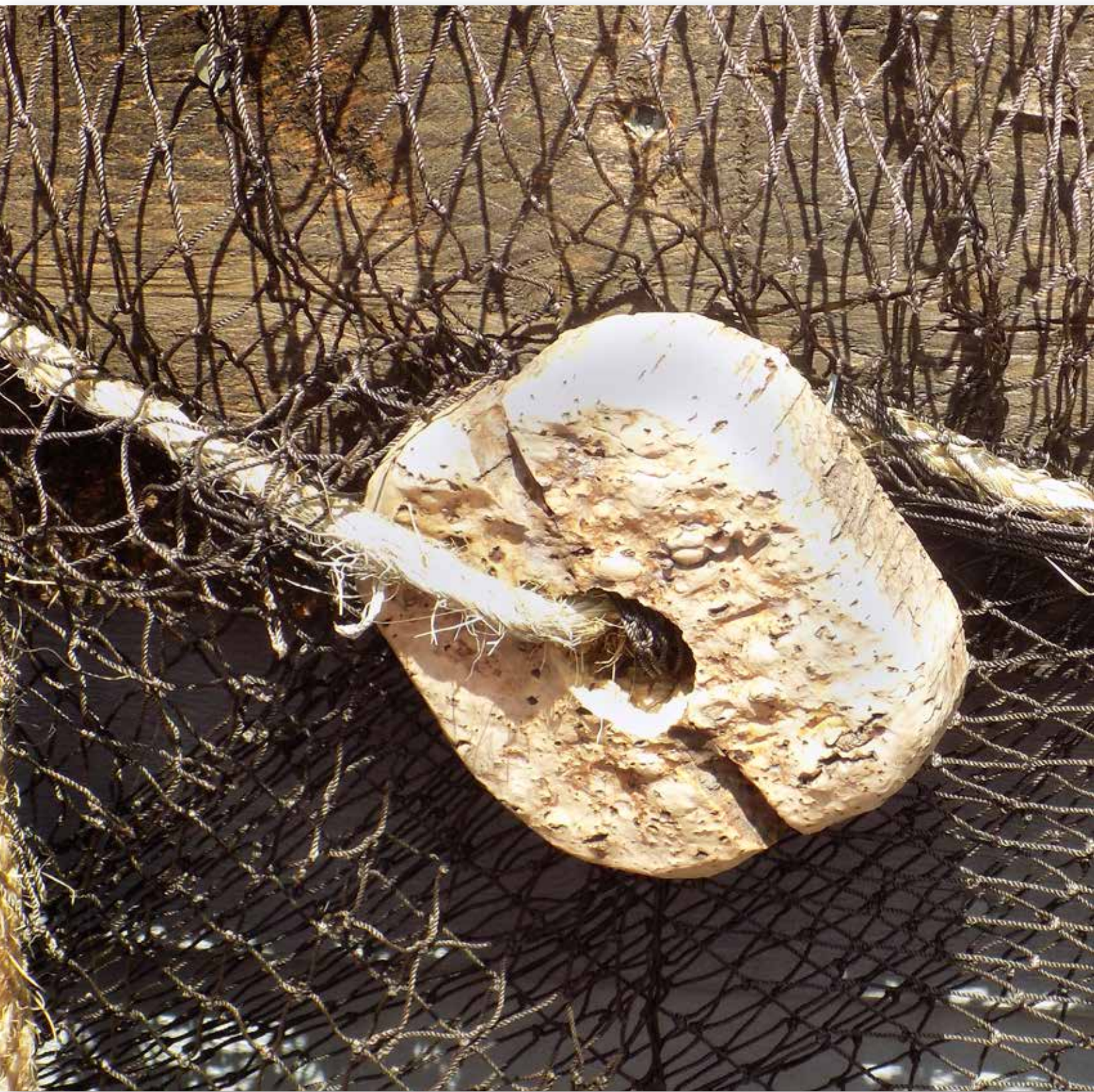
THE STRENGTH OF COMMUNITY

"I realized how big my support network was. I had a lot of family, friends, colleagues and people in the community who were there for me. Together we stand strong. And today, I have new friends that I have created, new people I have tried to help. I want to continue building a community where people living with melanoma are not alone."



WHEN YOU FEEL LIKE YOU'RE DROWNING

"When I was diagnosed, all I wanted was someone, anyone, to throw me a life preserver and pull me in – away from the fear and into a place where I could breathe and understand what I have just been told. Through the Foundation, I want to throw others a life preserver of hope and support."





CATCHING HOPE

“As a Foundation, we want to catch people early in their diagnosis. We also want to pull people who have been diagnosed into this network of support. Like the fishing net catches things and brings them back to the surface, we want to help provide the support people need to heal and take control of their illness.”



DANIKA GARNEAU



QUEBEC

Age: 24

Hometown: I come from Rouyn-Noranda in Abitibi, but I've lived in Montreal and Laval for the past 15 years

Occupation: Nursing Student

One Word That Describes Me: Resilience

Year Diagnosed with Advanced Melanoma: 2013

Why I Decided to Participate in this Project: To show the perspective of a young adult dealing with all of this, to raise awareness but also hope.

What My Reflection Project Means to Me: It means that some good can come from bad.





GRATEFUL FOR FAMILY AND FAITH

"Family is very important to me and it has made a huge impact on my journey with melanoma.

My Dad got a tattoo that says my name and the word H.O.P.E. I know he would take my place anytime if he could. Faith and hope have become a big part of our lives now."



EVERYONE IS DIFFERENT

"Melanoma often leaves me feeling different than my peers (much like the white in my lashes are different than the black). Even if I look like any other girl in her 20s, I am not. If you look closely, you see that my life is really different and I have to learn to live with it, like my white eyelashes."



THE SWITCH FROM EDUCATOR TO CAREGIVER

"This diagnosis changed my life. It changed my career. I was studying to be a teacher, but I decided to go into nursing, because nurses made me feel better. I never gave up, even while I was in treatment. It's taking me longer than others, but I'll make it and my face will be on that wall someday. It helps me to think I can give back to others."



THE MANY FACES OF MELANOMA

"I have mixed emotions on a regular basis. On one hand, I'm so happy and grateful because I found a treatment that is working, but on the other hand I have to live with the fear and anxiety for the rest of my life. It's always in the back of my mind."



THE PHYSICAL IMPACT IS INESCAPABLE

"Every three weeks I have to sit in a chair to receive my treatment. It's hard when you have school and work because the two to three days following the treatment I'm really tired. But the nurses are nice; I know all the staff, some patients, so it's also not that bad. I lost my hair, and that was hard."





SCARRED FOR LIFE

"The melanoma spread to my liver, lungs and bones. But it was one of my beauty marks that turned into melanoma first. The scar is shaped as a bird, almost like I was forced to "fly" into another world when I was diagnosed at 19."



SUSAN COX



ONTARIO

Age: 54 and happy to be here

Hometown: West Vancouver, B.C.

Occupation: Interior Designer

One Word That Describes Me: Loud

Year Diagnosed with Advanced Melanoma: 2007

Why I Decided to Participate in this Project: I'm no longer afraid to put myself out there, to participate in things, make waves, say my piece, and in doing so, I've found myself.

What My Reflection Project Means to Me: When I first saw my reflection project photos come together, I cried. These photos tell such a powerful story. These photos are me, my life and my time shared with melanoma through a lens. I want people to understand that we are surviving late stage melanoma and I want my pictures to provide a sense of hope.



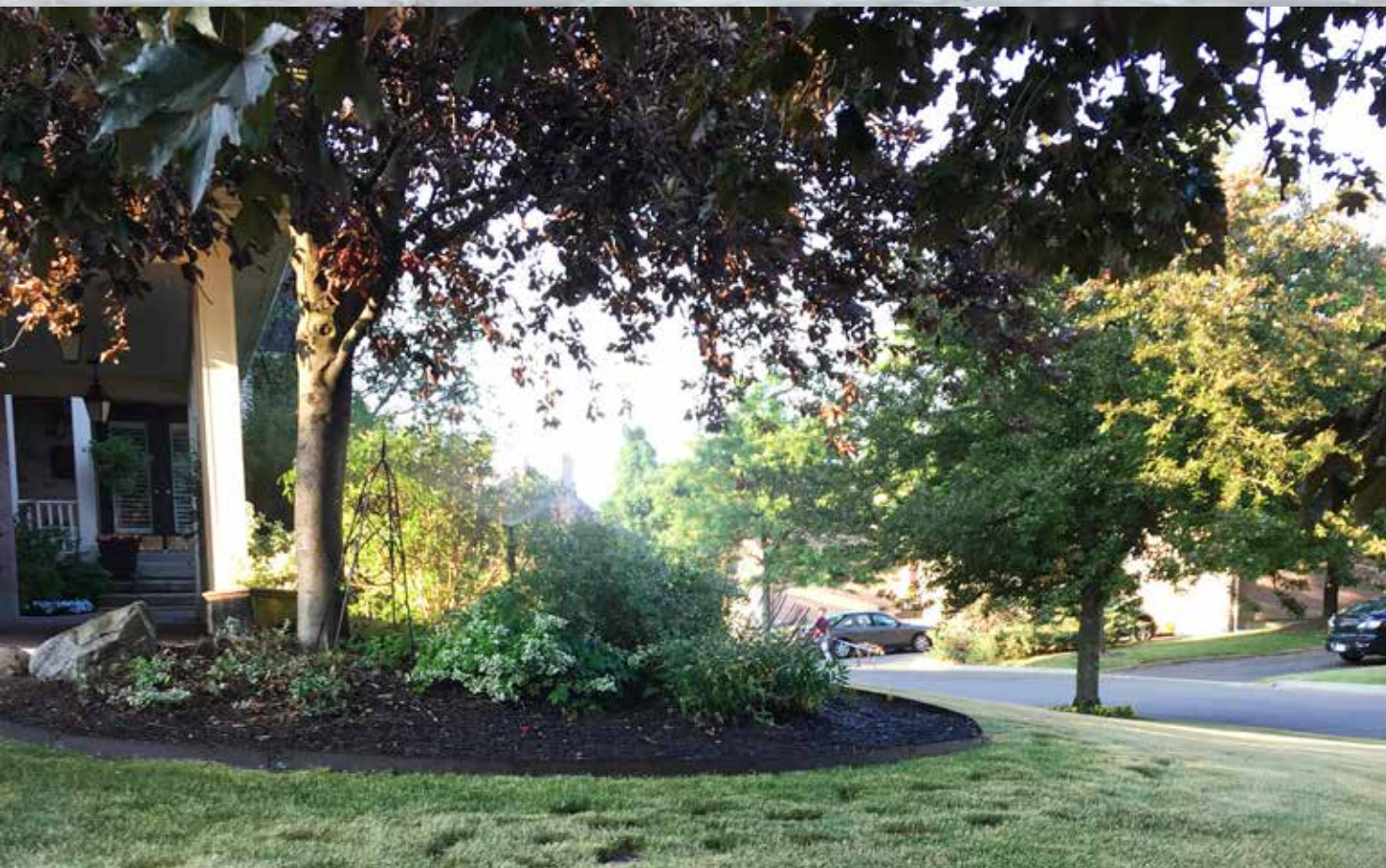
MY DREAM HOUSE

“When I was diagnosed with advanced melanoma, I was in tears. It absolutely demolished me. The stormy times and fear kept me from living my life vibrantly. I decided I needed to build my beach house and it’s now a reality. It’s a place I can go to relax and regroup, and express my passion for design. I may have never taken this risk before I fell sick.”

THE “BLUEBERRY” THAT CHANGED ME

“While time goes on, the physical and emotional impact of melanoma can fade, but it never really disappears. It’s something I’ll never be free of, but I can live with the scar and I can try to move on.”





THAT'S WHEN I KNEW IT WAS SERIOUS

"I remember glancing at my 12-year-old son who was in the doctor's office with me. The doctor told me I had more tumors. He told me people die from this disease. I thought, 'am I supposed to fight?' When you are diagnosed you are frozen in time and you live life between appointments, waiting until the day you can start living again. I believe I have come a long way to being able to live again."

TRAVELING FROM DARK DAYS TO BRIGHTER, HOPEFUL ONES

“My reality was doctor’s appointments and treatments. Since treatment, the days are brighter. The Fraser River is strong. It’s where I grew up. To me, Vancouver signifies everything that’s great – laughing so much your face hurts, family holidays, and my dream house. It provides me with a sense of hope.”





HELPING HANDS

"Being honest with my family about what I was dealing with made a difference in my journey. Everyone helped me get through this. My son is a very caring boy. My daughter always shows me she cares. My husband is always by my side. What could be more hopeful than more time with my loved ones?"





MIKE ALLAN



BRITISH COLUMBIA

Age: 58

Hometown: Prince George, B.C.

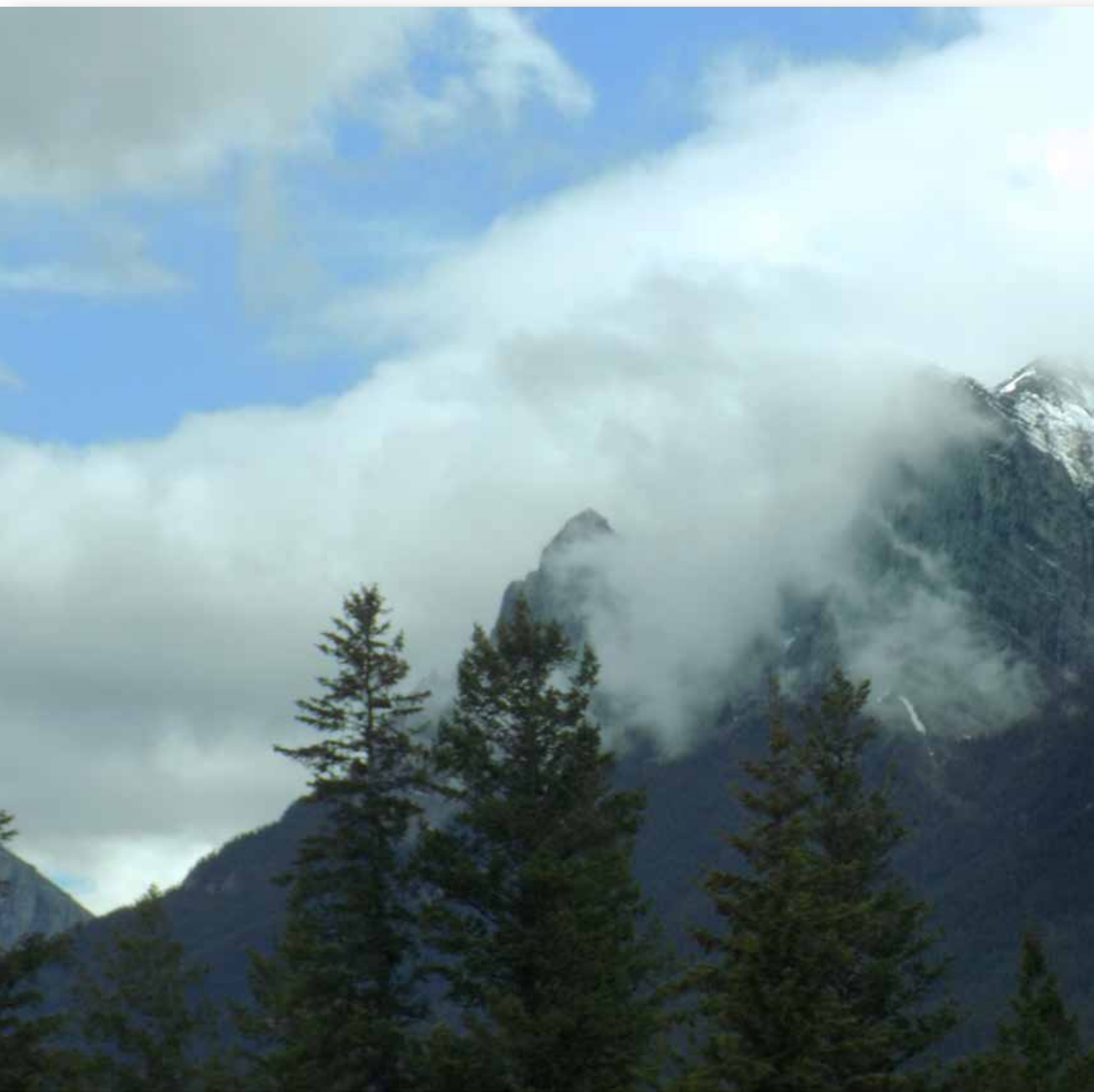
Occupation: Financial Service Manager

One Word That Describes Me: Survivor

Year Diagnosed with Advanced Melanoma: 2007

Why I Decided to Participate in this Project: I wanted to show people that there is hope after being diagnosed with melanoma.

What My Reflection Project Means to Me: Cancer doesn't just end for me. It's another step in the process of life. This project helps me and I hope it helps one other person realize that they don't have to die. No one said the journey was going to be easy but one person said that they knew how to keep me alive. I hung onto those words and still hang onto them now.





EVERY THREE WEEKS FOR FOUR AND A HALF YEARS

“My wife and I drove from B.C. to Edmonton for my appointments. It was our journey through the mountains; our journey with melanoma. The mix of beautiful weather and stormy weather reminds me of the physical and emotional impact of my disease – from the initial diagnosis, to physicians telling me there was no hope, to finding support and eventually hospice care. The drive was all that mattered though. We drove through white outs and torrential downpour to get me to where I needed to be.”



SNOW BARRIERS – LIFE BARRIERS

“So many things were blocking our path at different times. Even when we were told the road was closed, or there was no hope, we kept on going. We persevered. I knew I had to keep going.”



VICTORY RED

"I hit a milestone in my treatment. I wasn't supposed to make it to two years. Making it to my two year anniversary, I said to my wife, 'with all the driving to appointments, wouldn't it be nice to have a nice driving car?' I was surprised she agreed. The Camaro has given me a new life."



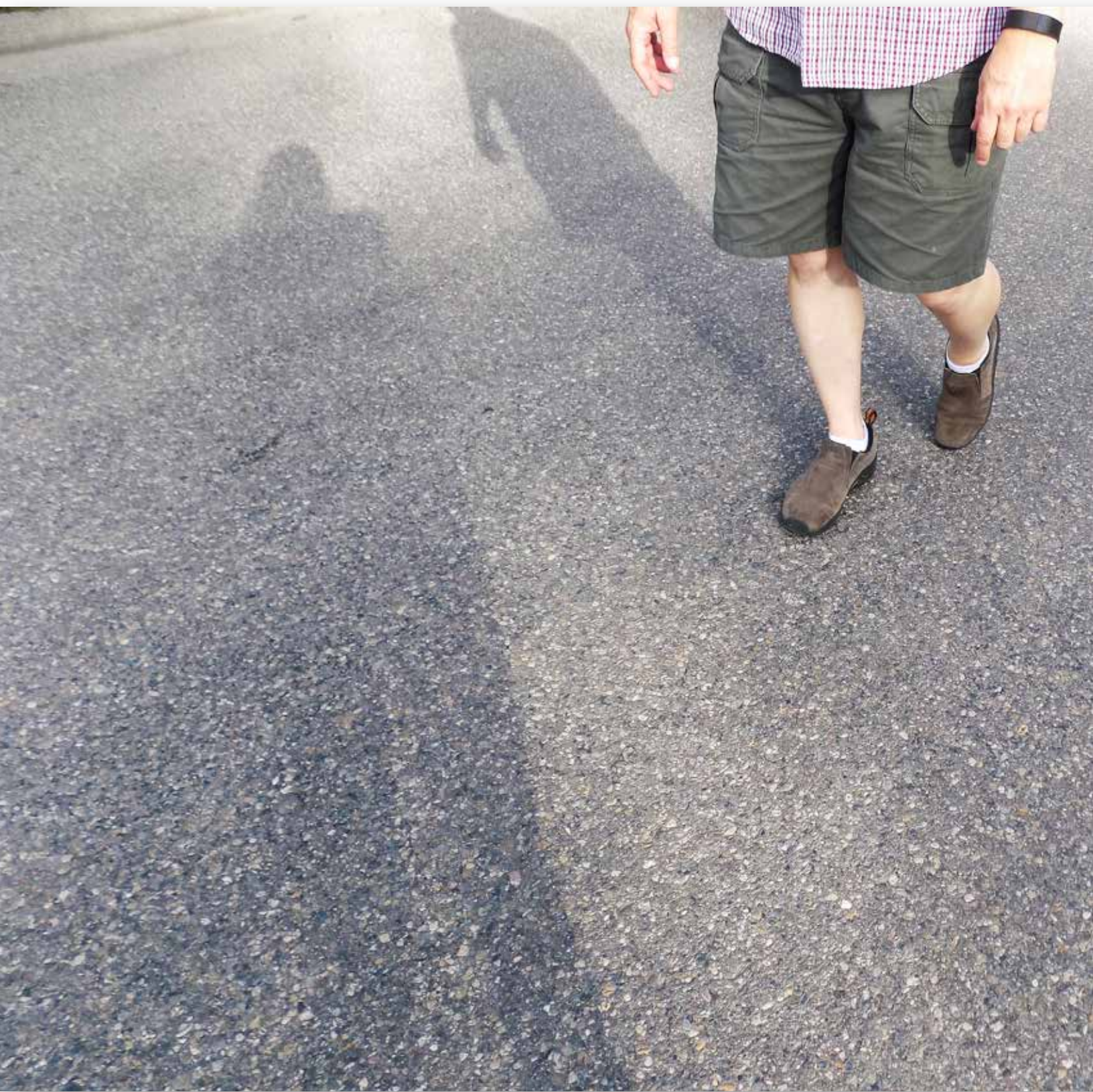
THE JOURNEY IS NOT ALWAYS DARK

"Sometimes no matter how tough the journey, there were beautiful days. No cars on the road, and a clear sky. This is how I felt later on in my journey. I started seeing that there is hope."



THE ROAD AHEAD

"I was able to start breathing on my own again. But it was hard to move. My muscles forgot. I loved walking before I got sick. But I had to start over again, and slowly. One day I walked to the end of my driveway, sat down to rest – these are the milestones that show you how far you have come."





COMING BACK TO LIFE

"There was a time I thought I had a death sentence. The melanoma was travelling throughout my body. I was beaten pretty hard. I was in so much pain. After treatment and leaving the hospice I was slowly able to walk again. This is where I made it. My legs worked. I finally got here. I feel grateful that I made it."



TERRY JAILLET



NEW BRUNSWICK

Age: 48

Hometown: Moncton, NB

Occupation: Investment Recovery Agent

One Word That Describes Me: Determined

Year Diagnosed with Advanced Melanoma: 2009

Why I Decided to Participate in this Project: I wanted to share my story with others and show how life and family can go on. Family is an important part in my journey, and can play in important part in other people's journeys as well.

What My Reflection Project Means to Me: My family has been a big part of my journey over the last seven years and has also been a big part of me being a survivor. Through this project I can see how far we have come as a family and it means so much to be part of the changes and accomplishments my family has had.



WORKING TOGETHER TO FIGHT THIS DISEASE

"Since my diagnosis in 2009, we changed our lives in so many ways, trying to be more health conscious. It brings us closer, helps us focus on family and cheer each other on. My wife took up running, and I am proud of her. She is setting an example, thinking about being healthy for our kids down the road."



MY SON ASKED ME, "ARE YOU GOING TO DIE?"

"Seven years ago I didn't think I would see my wife dressing my son for his graduation. He has autism, and this is a huge accomplishment for him. You know you are surviving when you witness these milestones. I survived to see my kids grow up."



SHE'S STILL DADDY'S LITTLE GIRL

"When my daughter was a little girl, she would get all dressed up in dresses and high heels. I would rock her to sleep. On the night of her prom, it reminded me of that time. She's all grown up now, and she's become a beautiful woman. I now picture her getting married. Being a dad gives me fulfilment, and helps distract me in some ways."



I DON'T THINK ABOUT HOW MUCH TIME I HAVE, I LIVE EVERY DAY FOR EACH DAY

"I hit a major milestone – 25 years with the company I work for. I felt a great accomplishment when I was inducted into the 25 year club, especially since I stopped working for two years when I was sick. It reminds me I am a survivor of cancer."





THE LITTLE MOMENTS THAT MATTER MOST

"Before I would think about the unknown and it was scary. Where would my cancer go next? Today it's about not worrying. I want to see my wife not worry. I want to do more reflecting in the moment – moments like a nice evening out at the park with my family."



NATALIE RICHARDSON



ONTARIO

Age: I just turned 40 yahoo! Was diagnosed at age 37

Hometown: Meaford, ON

Occupation: Cash Office/Payroll Manager

One Word That Describes Me: Intrepid

Year Diagnosed with Advanced Melanoma: 2014

Why I Decided to Participate in this Project: To share the roller coaster journey that is living with melanoma, to bring awareness to the dangers of sun over-exposure, and to give hope to others fighting the same battle.

What My Reflection Project Means to Me: It brings awareness to the fear I have experienced and conquered, and it helps bring closure to my first experience with melanoma skin cancer. I am afraid my journey is not over, but when it comes back I will be able to draw strength from this collection of images and have hope that I can fight it again.



JUMPING THE ROCKS

“My 14-year-old twin daughters and I spent a lot of time at the waterfront in Meaford, jumping the rocks to get to the lighthouse. The day I was first diagnosed was the first time I wasn’t care-free. I felt frozen, and as soon as I was diagnosed, that was the end of jumping on the rocks.”



HOSPITAL WALLS

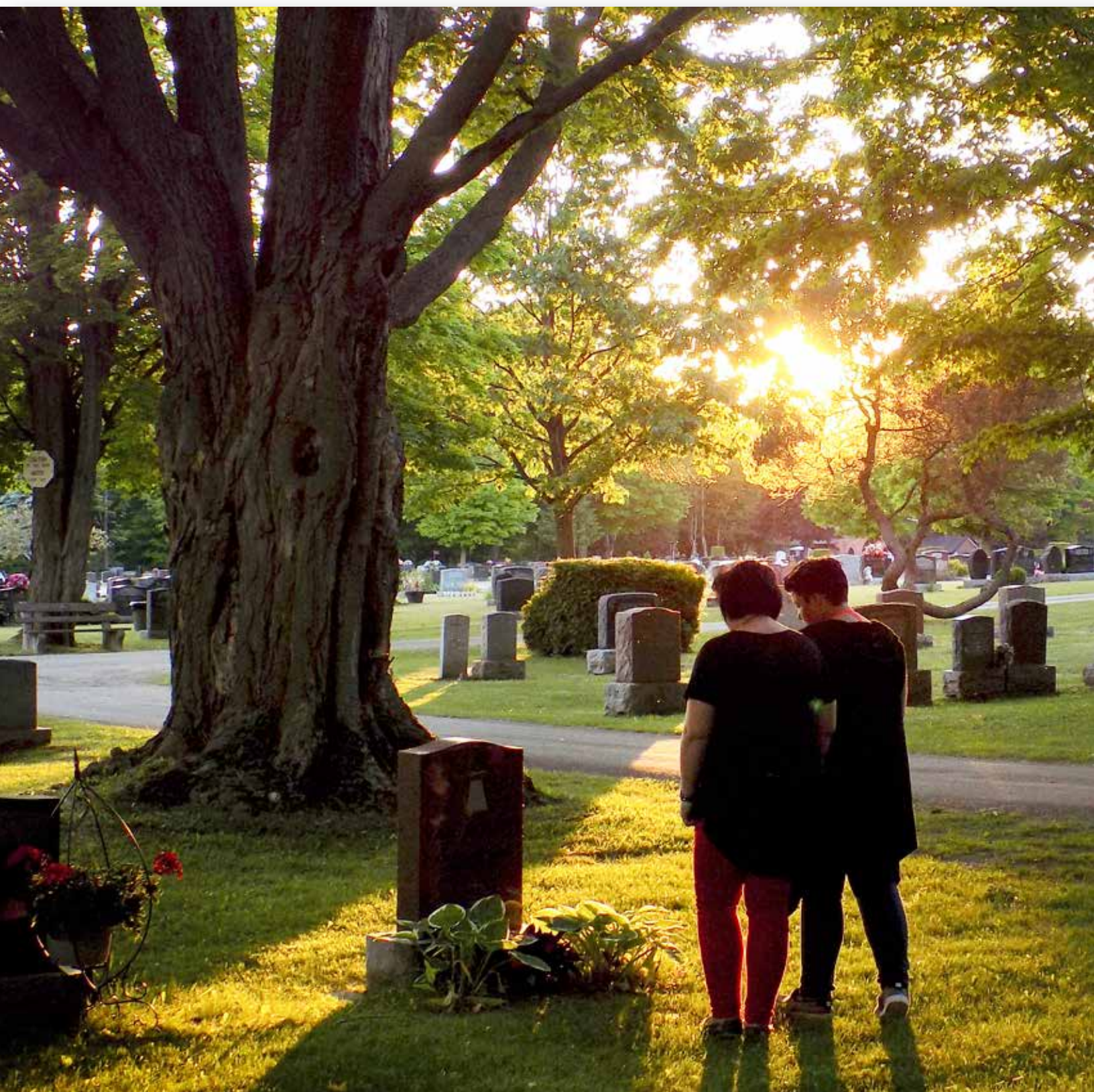
"We passed through the hospital hallway over and over and over for treatments. It was a long journey to get to the other side."



UPS AND DOWNS

"Cat scans, surgeries, treatments, bed rest. It all took a toll. When I was sick, I couldn't even climb the stairs at the hospital. It felt like a maze. It was a constant reminder of my illness and the physical and emotional toll the disease was taking on my body and my life."







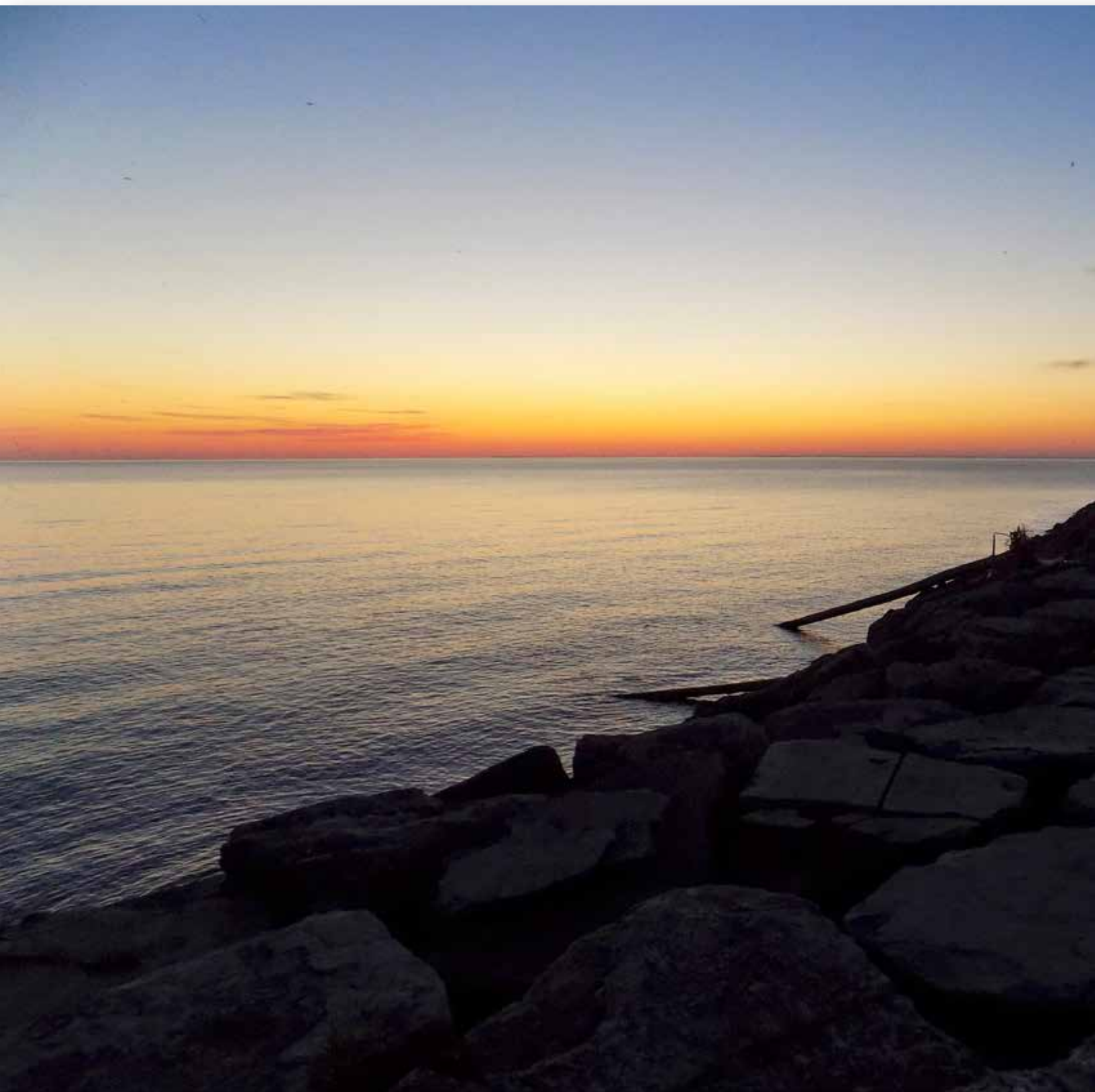
MY GREATEST FEAR...

"There have been some really dark times and what scares me most is leaving my daughters behind. The thought consumed me, made me anxious and it felt like an uphill battle. My daughters told me to stay strong. I didn't want to leave them, so I found the strength and inspiration to keep going."

RECOVERY STAIRS

"I remember not being able to physically climb stairs, but today, after treatment, things are getting better and easier to navigate. I can't always see what is around the corner, down below or what will be there when I reach the top, but I still take the steps to get there. One step at a time, one day at a time."







FEELING ALIVE

"A big milestone in my journey and in my recovery was being able to jump the rocks again. My hope is for a long future, one where I can see both my girls graduate from university. The sun is rising and the light at the lighthouse is on. I see hope and a new dawn."



ABOUT MELANOMA

Melanoma is a personal journey, different for every patient and every friend or family member. It's a personal disease, with different causes, symptoms, courses of progression, treatments and prognosis. It's useful to know about the disease as you make your own personal journey or support someone you love with advanced melanoma.

Melanoma is a type of skin cancer most commonly caused by damage to the DNA in a certain type of skin cells called melanocytes, often due to exposure to ultraviolet light.¹

This damage can cause skin cells to form cancerous tumours, but if caught early it is almost always curable.² However, if left untreated, melanoma can spread, or metastasize, to other parts of the body – such as the brain, bones, liver, and lungs.³

When melanoma cannot be fully removed by surgery (stage III unresectable), or has metastasized (stage IV), it is known as advanced melanoma⁴ and is the most serious form of skin cancer.⁵ Until recently, advanced melanoma was a disease with limited treatment options and a poor prognosis. In the last few years, however, significant advances in the molecular understanding of this disease have allowed the development of novel and promising treatments.⁶ However, advanced melanoma can still be much more difficult to treat than melanoma that remains localized.⁷

ADVANCED MELANOMA IS NOT A “ONE SIZE FITS ALL” DISEASE

Advanced melanoma (unresectable or metastatic melanoma) varies from person to person due to changes in the genes that are unique to each person with the disease.⁸ In fact, melanoma is one of the cancers with the highest frequency of mutations.⁹ There are several melanoma mutations that you can be tested for, and identifying your form may influence the choice of treatment to help you control this disease.¹⁰

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