# HOPE & COPE

2018 – 2019















## With you throughout the cancer journey

Jewish General Hospital

## Who we are

Close to 40 years ago, **Sheila Kussner** founded Hope & Cope to **help people cope** with the physical, emotional, spiritual and financial impact of **cancer**.

We harness the innate wisdom and genuine compassion of **450 cancer-experienced volunteers** who are a source of inspiration and comfort to people at every age and every stage of cancer.

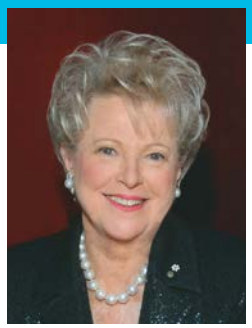
Along with generous donors Christine and Herschel Victor, Hope & Cope established and supported **Quebec's first Chair in Psychosocial Oncology** at McGill University, and is proud to be a leader in peer-based psychosocial care, contributing knowledge and research to this evolving field.

Hope & Cope is **100% funded by and accountable to the community we serve**.

Since 1981, **over 30,000 patients** and their families have benefited from our services.

**We currently welcome over 1,300 new users per year**.

Our Wellness Centre – the first hospital-affiliated cancer wellness centre established in Quebec – is a place of learning, discovery and hope.



### SAVE THE DATE

**Help us keep our founder's legacy alive. Mark your calendar for our Butterfly Ball on August 25, 2020, honouring our founder, Sheila Kussner's retirement and celebrating 40 years of giving hope wings.**

# Message from the Chair



CHALLENGE, CHOICE and OPPORTUNITY - these are three of my favourite words, and I use them often when I refer to Hope & Cope. We have a long history of facing challenges, adapting to change, making good choices and finding opportunities for reinvention and strategic reflection.

Five years ago, the Board identified succession planning as our greatest challenge but also as an opportunity for new leadership and new ways to meet the needs of the next generation of donors, users, staff and volunteers. Leadership transition started with my retirement as Executive Director and the passing of the baton to Danielle Leggett. We are now preparing for the retirement of our Founder, Sheila Kussner. Yes, Sheila is, indeed, retiring next summer!

We will be hosting a Butterfly Ball in her honour on August 25, 2020. Save the date in your calendar now – it will be a sell-out event! The Ball will mark the start of Hope & Cope's 40th year as a nationally and internationally recognized cancer support organization – a truly remarkable achievement. Over these years, we have helped countless thousands of people when they needed us most. Sheila has been our guiding light, mentor and principal fundraiser all these years, but she has always been the first to say that she did not and could not do this alone.

We have the wonderful opportunity to keep Sheila's vision alive and thriving for our children and grandchildren. The Board has initiated a Legacy Campaign to ensure Hope & Cope's future and we invite you to be part of it. All gifts, big and small, make a profound statement. Your gift will reaffirm your belief in our mission of helping people cope with cancer and in the importance of ensuring that Hope & Cope remains a vital part of our community for generations to come.

On behalf of the Board, thank you for your ongoing support. **Let's accept the challenge of keeping Sheila's legacy going strong** and let's get out our dancing shoes for the Butterfly Ball next August!




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The opinions expressed in this publication are solely those of the contributors. Please note that to our knowledge at press time, all information in this publication was accurate.

# INNOVATIVE PROGRAMS

**Since Hope & Cope began in 1981, innovation has been our lifeblood. Where our research shows us there is an opportunity or a need, we address it. Here are two programs introduced within the past year.**

## Virtual Reality Goggles Whisk Patients Away

Time is a luxury that palliative care patients do not have. Yet, thanks to virtual reality (VR) goggles, a project introduced by Hope & Cope, patients can travel to a favourite vacation spot or back to the land of their birth, all from the comfort of their beds on Côte Ste. Catherine Road.

"We were looking for new therapies, to complement what we already offer," explains Rifka Hanfling, Palliative Care Coordinator for Hope & Cope. Sophie Guérin, a volunteer and medical student, read about virtual reality goggles, and the pair researched the idea. This is the first time VR has been introduced to Quebec.

With the approval of Dr. Bernard Lapointe, Chief of Palliative Care at the JGH, Rifka borrowed a set of VR goggles and asked patients what they would be interested in viewing. "We have a diverse immigrant population," says Rifka. "Some patients wanted to go back to their home country one last time, while others preferred to view nature scenes." Rifka and Sophie downloaded 25 videos suitable for VR viewing.

Patients' physical reactions were observed and recorded. They were asked questions about their emotional and physical state both before and after viewing the videos. The results were dramatic, according to Rifka. "Often, when we first walked into the room, patients were distressed. As they became immersed in the virtual reality world, their breathing became more relaxed, the tension left their face, they smiled, some even began chatting about what they were seeing."



These effects lasted an average of two hours. Families used the goggles, too, allowing them to experience a trip together. "We saw how virtual reality not only improves the quality of life for patients, it is also therapeutic for the family, providing a positive memory and a beautiful legacy for them to hold onto," says Rifka.

With the guidance of Dr. Carmen Loiselle, Hope & Cope's Scientific Director, and research manager Jacqueline Vachon, Rifka and Sophie are developing a protocol for a research study designed to show the merits of incorporating VR as part of the medical treatment in a palliative care setting. Dr. Bernard Lapointe has agreed to be the Principal Investigator on this study.

**Currently, there are 2 virtual reality goggles on the unit, several interfaces (sanitized after each use to avoid infection) and 25 videos. The goggles cost $400 apiece. We would like to offer this service to more patients and broaden the selection of videos. Cost = $5000**

**"We always dream of visiting places that mean a lot to us. Suddenly, disease comes crashing down and you're very sick. With virtual reality, you are transported from a bed to the top of a mountain or the streets of Rome or Jerusalem. What a great way to introduce this technology in the care of our patients, through the wonderful presence and listening ear of our volunteers!"**

***— Dr. Bernard Lapointe***

## New Resource for Talking to Children About Cancer

Among the many difficult questions parents face when diagnosed with cancer is "What do I tell my children?" Hope & Cope is addressing this issue through a great new resource: a series of three booklets on talking to children about a parent's cancer. Each covers a different phase, from diagnosis to advanced cancer to grief and loss.




"So many patients would ask me, How do I tell my kids?" explains En famille Coordinator Sandy Lipkus, who initiated and oversaw every aspect of the project. "There definitely was a need for a professionally designed resource to guide parents in these difficult conversations."

Written in clear, simple language and available in English and French, these beautifully illustrated, meticulously researched booklets provide tips for talking to children of all ages and developmental stages. For example, explaining cancer to a 4 year-old who believes in magical thinking requires a different approach from that used with an adolescent who understands the gravity of a cancer diagnosis. The booklets include a glossary of cancer-related terms in child-friendly language and sections for single parents and children with special needs.

The response from parents as well as oncology health care professionals has been so positive that Sandy continues to receive requests for the booklets from patients and health care professionals in Quebec and across Canada. She also has been invited by colleagues at the JGH to present the project at team meetings in the radio-oncology and social work departments.

## Executive Director's Report



As I look back on my first year with Hope & Cope, one of the things that I most impressed with is the depth and breadth of the programs and services we provide to our community of users.

In this annual review, three inspiring Hope & Cope users share their personal challenges and unique journeys. Each of them benefited from our programs in very different ways but they all have one thing in common – the vicious impact cancer has had on their lives. The reality is there are countless similar stories, and they are all equally important. Irrespective of the story, our team of volunteers and professional staff is always there for support along the way.

Hope & Cope is a force – a force to support you, a force to accompany you, a force to advocate in the community for you, and most importantly, a force to help you live well.

The world of cancer care and support will continue to evolve – needs change, new research and trends emerge, demographics shift, and all of these inform our programming choices.

Thanks to the ongoing generosity of Hope & Cope's loyal donors and our recognized leadership in psychosocial programming, we are at the forefront of these changes, giving us the opportunity to have a positive impact on patients and their caregivers. In the past year, we piloted new programs like Focus on the Future, increased access to popular services like Reiki and offered our staple programs like CancerFightClub, which meets the unique needs of the young adult population.

### Our commitment is always to be there

for those who come to us in need. Hope & Cope's effective programs and services, backed by research, have a lasting impact on our community. It is this impact that makes us accountable to all our stakeholders.

Thank you for another great year and stay tuned for more great things to come!

Danielle Chaggett



# Anna's Journey: Committing to Wellness One Step at a Time

By Hena Kon

For as long as she can remember, Anna Babanicos has been a solution-oriented person. No stranger to health challenges, including miscarriages and a horrific multi-vehicle car accident when she was 20 that left two people dead and shattered her hip and knee, Anna refuses to dwell on the negative. From a very young age, her husband and childhood sweetheart instilled in her the importance of looking at the bright side. "There's always somebody worse off than you," she explains. "Yes, I lost my three babies but I am grateful for our son – I call him our miracle baby."

So when Anna was diagnosed with breast cancer in 2015, shortly after Christmas, she was upset, but took it in stride. "I knew I just had to take it one day at a time and do whatever I could to get better," she recalls.

On the advice of her doctors, Anna chose to have a lumpectomy, followed by chemo and radiation treatments, and oral medications. Unfortunately, the treatments left her with complications including radiation pneumonitis, severe neuropathy (nerve damage causing crippling pain and weakness in her hands and feet), lymphedema (breast swelling) and chemo fog (chemotherapy-induced memory loss and concentration problems).

Referred to Hope & Cope by her doctor, she grabbed several pamphlets describing our services and was intrigued by our Wellness Centre, but too tired to follow through. She remembers the day that changed her life, thanks to Esther, a radiation-oncology volunteer. "I was in so much pain from the neuropathy. Esther encouraged me to go to the Centre right away and from the minute I walked in, I knew I was in good hands."

## Nearly 1 in 2 Canadians will develop cancer in their lifetime

**The Canadian Partnership Against Cancer (CPAC) recently released a patient experience report on over 13,000 people who completed cancer treatment:**



**7** in **10** patients reported having **emotional concerns** after treatment ended such as worry about cancer returning, depression and changes in sexual intimacy.



**8** out of **10** patients had **physical challenges** after their treatment ended, including increased fatigue, and changes in sexual function and fertility.

After being assessed by our ActivOnco team in September 2016, Anna was given an exercise program to follow in the Centre's fully equipped, supervised gym. It was here that Anna focused on regaining her strength in a supportive and motivating environment. "Exercising in the gym really helped me focus on listening to my body," she says.

Anna is deeply grateful to the volunteers, gym interns and staff, all of whom have been unfailingly polite, gentle and calm. The complications that she suffered forced her to stay home for months at a time. Yet she knew that she could always count on Hope & Cope. "The follow-up calls by the exercise program coordinators checking in to see how I was doing showed me that they cared, I wasn't alone and that I was welcome to come back any time."

In addition to working out in the gym, Anna participated in other activities such as tai chi, Reiki, our coping skills workshop, and a post-treatment program called Focus on the Future. She was particularly impressed with the speakers, the volunteers who led the program, the structure and the content of this 6-week series that offers sessions on topics such as nutrition, exercise, returning to work and coping with fears of recurrence.

**"This course helped me put together everything I learned at Hope & Cope. It gave me a roadmap to improve my health,"** Anna explains. She adds proudly that she is already on her way, having cut out sugar and salt from her diet, which improved her neuropathy by 70%.

Referring to the cancer survivors she has met at the Wellness Centre, Anna concludes, **"Everybody here has a story. Sometimes we think we may have it bad but we can't imagine the hell that other people go through until we hear their story. The beauty of Hope & Cope is that we learn from and encourage each other."**

***"Over the years, we have met countless patients who had serious concerns about life after treatment. We created a pilot program in 2018 to offer these patients a chance to connect with others who have similar concerns as well as practical strategies for moving forward with confidence after cancer. Feedback on the pilot was so positive that the 6-part series called Focus on the Future is now part of our core programs."***

*— Hinda Goodman, Oncology Program Coordinator*







# Sisterly Devotion through Caregiving

By Marylin Smith Carsley

Accepting the cancer diagnosis of a loved one is so devastating and absorbing that this new reality can be daunting. Fortunately Hope & Cope lends a compassionate hand to all family members. Not only is the patient addressed, but the caregiver is included, receiving invaluable support and learning how to assist in this altered lifestyle. When that caregiver just happens to be the younger sister, that personal connection is fraught with emotion.

Isabelle, the younger sister, recalls when her sister, Julie, at the age of 39, lost her valiant fight with breast cancer. Initially, Julie and her family had faced fear, isolation, and helplessness because Hope & Cope's resources were not known to them. Treatments of chemotherapy and radiation did not eradicate the cancer and after a brief remission, Julie was diagnosed with metastatic breast cancer. Isabelle remained solidly by Julie's side, relinquishing her own needs to care for her sister.

**"I was her sister first, but as her caregiver, I needed to understand my new place. My sister had always been the leader, but the roles were now switched and that was also hard for us to accept."**

Julie's passion for life broke the circle of cancer isolation. She believed in the importance of relaying her message about living with a chronic illness. She also tried to encourage Isabelle to live her own life away from her illness. Through the wonderful support of Hope & Cope, Julie emerged as a community leader in the CancerFightClub – a unique program for young adults ages 18 to 39 with cancer; she organized retreats, spoke at conferences, initiated the Cooking Club at the Wellness Centre and acted as a peer mentor. The annual Hope & Cope Family Day BBQ became special for Julie's young daughter as she was able to encounter other children experiencing cancer in the family.



Isabelle remained determined to help Julie fight this disease. With admiration, she would witness her sister's inner strength emerge through her ongoing involvement with Hope & Cope. Isabelle was there every step of the way, keeping a detailed medical notebook outlining everything Julie needed during her final eight months. Hope & Cope always supported Isabelle, understanding her solitary role as a caregiver.

**"Hope & Cope really opened my eyes, showing me that I was not alone,"** Isabelle commented. The Young Adult 2013/2014 Metastatic Cancer Retreats were so enlightening for Isabelle as she met other caregivers. She also learned at that time that she must remain completely in the present and not imagine the future. There was a sense of community and understanding in these

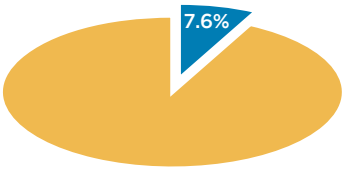
gatherings, where Isabelle discovered a place to share her frustrations, experiences and conflicting emotions. Isabelle greatly appreciated the support and the listening ear, in a world where people understood her.

Towards the end of Julie's life, Hope & Cope sent Isabelle and the family complete meals from Kerry's Kitchen, and took care of the parking at the Jewish General Hospital. Every Hope & Cope interaction eased the distress for both patient and caregiver.

Isabelle discovered that not too many people her age were caregivers. Reaching a deeper level than the sister relationship, Isabelle would not have it any other way. As heartbreaking as losing her sister was, and through all their disappointments, Isabelle felt so privileged to have spent this time with Julie.

**"She was my best friend and I have no regrets. I am and will always be her caregiver."**

## 30 young adults attend Hope & Cope's annual retreat




**On an annual basis, approximately 7.6% of young adults (15-39) in Canada are diagnosed with cancer**

**The burden of cancer in young adults*:**

- delays in diagnosis means the cancer has grown large or has spread
- financial concerns
- social and emotional issues – this tends to be a time of great change in a person's life and a cancer diagnosis can throw this into disarray
- impact of treatment on fertility
- interrupting studies or careers
- loss of independence
- lack of research

*Source: Adolescents & Young Adults with Cancer, a report by the Canadian Partnership Against Cancer, April 2017

## Excerpts from a Eulogy by Suzanne O'Brien



"After a cancer retreat a few years ago for young adults living with metastatic cancer, Julie advocated strongly that an annual retreat was not enough. She helped me develop Club Mets – small weekend retreats 3-4 times a year at the cottage... It was a safe space for tears and laughter, food and fun...

Julie wrote and translated the CancerFightClub newsletter and managed the social media. She had endless energy for the cancer community even when she did not have enough energy for herself...

Julie had a mission to talk to healthcare professionals about living with metastatic cancer and she took every opportunity to advocate, not just for herself but for others. She was part of a film "The Power of Me; the Power of We" talking about empowerment and legacy which has been shared at international conferences and has become a powerful teaching tool for young nurses...

**Julie was a teacher, a fighter and a leader right to the end..."**




# Jean Sabourin: An Unconventional Journey

By Guy Djandji

When Jean Sabourin was diagnosed with stage 3 esophageal cancer, he was understandably distraught. His brother's passing from the same cancer several years earlier was uppermost in his mind. Jean knew that he needed time to reflect on his physical and emotional state and to weigh the treatment options recommended by his medical team. He instinctively resisted the pressure to go ahead immediately with radical surgery, preferring to examine other possible avenues before making his decision.

Over a period of several months, Jean immersed himself in researching, reading, analyzing and evaluating traditional medical treatment options as well as less conventional therapies. "I went shopping and visited the CHUM,  the JGH and the Glen. I had met several specialists at the JGH who referred me to Dr. Ferri at the Glen."

Ultimately, Jean chose an eclectic path combining specific therapies with traditional medical approaches that he believed would offer him the best chance for survival. He enrolled in an immunotherapy research study in tandem with chemotherapy treatment prior to undergoing surgery in October 2018.

Upon receiving his diagnosis, Jean completely transformed his eating habits as he was convinced that what he put into his body would have a direct effect on reducing the cancer's growth.

One year after his fight began, Jean discovered Hope & Cope through a volunteer in the oncology waiting room. He was instantly reassured by the warm welcome he received at the Wellness Centre.

**"I discovered an environment where I was respected, where people listened to my concerns and understood my needs – an organization that takes care of people in the same situation as me. I no longer felt alone," he explains.**

**"There are hundreds of studies showing real, tangible benefits of exercise for patients with a variety of different cancers and at different stages."**

*— Excerpt from Harvard Health Blog*

Following registration at the Centre, Jean became a "regular", participating in a wide variety of activities. From this first visit, Jean's visits to the Centre and commitment to his wellness plan were motivated by several factors: the reputation of the hospital, the great people he met, and, "above all, the fact that Hope & Cope is open to anyone with cancer, without discrimination."

Jean attended several support groups where he was welcomed with compassion, respect and acceptance. "This empathy and understanding were remarkable. I never felt judged, despite my unconventional treatment choices."

Over the ensuing months, Jean registered for several activities and workshops. Two of these, in particular, greatly reduced his anxiety and stress levels: the weekly *Relaxation, meditation, visualization* class and Reiki sessions – a Japanese method of channeling energy to achieve peace of mind and physical well-being. "Working on the mind-body connection allowed me to develop a sense of inner calm that helped me to heal," he recalls.

Jean derived tremendous benefit from a personalized exercise program in the Wellness Centre gym. "Oxygenating my body stimulated my immune system to fight the cancer," he states. Jean also participated in the Centre's cooking classes, gardening workshops and dance classes.

What Jean appreciated most of all was the sense of camaraderie he found at the Wellness Centre.

**"Here, I was part of a community where everyone faced similar problems, where I was listened to and supported in all of my efforts. I was always well received, even though my journey was unconventional. It was like being part of a fraternity. It's good to know that there's a place like this right here in Montreal."**

- From June 2018 - June 2019, **113 Reiki sessions** have been offered, making this one of our most popular offerings at the Wellness Centre
- Over **230 fitness evaluations** and **active lifestyle prescriptions** are given by our ActivOnco team at the Wellness Centre each year
- Each year, the gym at the Wellness Centre receives close to **3,000 visits**



# Live Like a Pro, Play Like a Pro



Antony Proteau had a close-knit group of childhood friends, a competitive spirit, a love of hockey and a huge heart. When he died of cancer at the age of 23, his family and friends were devastated.

"Pro was special. Even as a young man, he was focused, responsible and committed to doing the right thing," said Timothy Schiavi. Searching to create meaning out of such a tragic loss, Tim and his friends, James Lavinskas, Keif Orsini, Matthew Chaussé and Richard Ribaya, established the Antony Proteau (AP) Fund. Their goal was to keep Antony's memory alive while raising funds to support Hope & Cope's unique programs for young adults with cancer such as our annual retreat in the Eastern Townships.

The AP Fund organizes two signature events per year – a sophisticated gala in March and an action-packed ball hockey tournament in June. Both events attract a growing crowd of dynamic young professionals.

Cyntia and Charles, a young couple who attended the retreat last February, were grateful for the experience. "For the first time, I could talk with other guys about the anger, guilt and depression I was feeling," Charles told guests at the 2019 gala. Cyntia, who had suffered a miscarriage, the shock of diagnosis and the rigours of cancer treatment all while caring for their one-year-old son, noted that the retreat had a profound impact on her marriage and family life. "We owe so much to Hope & Cope and to all of you," she said.

# Walk-a-thon Has Staying Power

The Dorval, Sources and Saint-Henri Auto Parts annual walk-a-thon has it all: great atmosphere, mouth-watering food, beautiful scenery, and most importantly, staying power.

The walk-a-thon is the brainchild of Alex Trichas and his cousins Nick, Chris and Andre Dimopolous, a close-knit family that shares a profound desire to give back. Since its inception in 2008, this scenic, family-friendly 7 km event has raised over $650,000 to support Hope & Cope's Cancer Exercise Program at the Wellness Centre.

Relying on their right-hand man, Gus Anagnostaras, and their extensive network of contacts in the automotive industry, generous suppliers, employees, family and friends, the organizers cover all the costs, which means that 100% of the proceeds go to Hope & Cope.

"We see the need and are inspired by the courage of the patients who come to Hope & Cope," states Alex. "That's why we'll keep doing this until, hopefully, one day, we will see the end of this disease."

Adds Nick, "The first time we came here to see the gym and to talk with the patients, we were blown away by your facilities and by the impact Hope & Cope has on so many people in our community."

## A Family Affair



*Rosa Maria Cisneros Calderon was one of several participants who was happy to train in our gym, participate in the walk-a-thon and raise funds for Hope & Cope, a cause she took to heart. Sadly, she passed away in August 2018, just two weeks shy of the walk. Before she died, Rosa extracted a promise from her children that they would walk every year in her memory. Not only have they kept that promise, last year, the entire extended family proudly wore special T-shirts printed with Rosa Maria's picture – a touching tribute to Rosa's life and spirit.*

# Giving Back through the Power of Song

Gail Issenman was a loving mother of three young children and enjoying a thriving career as a singer and vocal coach when she was diagnosed with an inoperable brain tumour. After undergoing surgery to prepare her for radiation treatments that would shrink the tumour, she was instructed not to strain her voice, as the placement of the tumour changed the pressure in her head and singing too much could have life-threatening consequences.

Gail was referred to the Hope & Cope Cancer Wellness Centre's supervised gym because we had the only exercise option for her – a recumbent bicycle. The Centre became more than just a place to keep active – it became her second home, where she found a community of cancer survivors who understood and supported each other.

Following her recovery, Gail was determined to give back the best way she knew how – by recording an original song called *Love Yourself*, and donating the profits of the song to the Wellness Centre. An upbeat video of the song, shot




at the Wellness Centre and in her N.D.G. neighbourhood, was launched at Hope & Cope's annual Holiday Potluck and Sing-along last December.

# Tell Cancer to Take a Hike

Launched in 2018, Tell Cancer to Take a Hike is a unique fundraiser chaired by Hope & Cope Board member Howard Stotland, with fellow Board member Alice Lehrer as vice-chair.

The idea was the brainchild of Howard, who had climbed Kilimanjaro several years ago on behalf of another charity and relished the idea of taking Hope & Cope to the top of the world. Intrigued but unable to commit to a trip to Africa, Alice met with Howard and two other volunteers to flesh out the idea of adding a second option for those who enjoy hiking but prefer to stay closer to home. The result was *Kili chez nous*, a series of local hikes in beautiful surroundings offering breathtaking scenery.

"Bonding, training and hiking with a team of like-minded people and raising money for a cause we all believe in so passionately has been an incredible experience," says Howard, who is responsible for soliciting sponsorships. He notes that in 2018, more than 100 enthusiastic participants and sponsors collectively raised over $550,000 to support Hope & Cope. **The 2019 edition now underway is on track to exceed last year's total, with a climb of Mount Kilimanjaro planned for January 2020.**

As a cancer survivor and a volunteer who leads Hope & Cope's highly successful weekly Mourning Walks on Mount Royal for those who lost a loved one to cancer, Alice is touched by the generous response to this fundraiser. "Knowing how important Hope & Cope is to patients and their families, it is really heartwarming to see 40 people come out for a hike, challenge themselves and enjoy the rewards of helping cancer patients with every step they take," she says.





# PHOTO GALLERY · GALERIE DE PHOTOS





















