

# spotlight



NEWS FROM THE FOUNDATION WORKING TO END MELANOMA

MARCH 2020

## **WOMEN WHO INSPIRE**

**CELEBRATING  
#WOMENAGAINSTMELANOMA**



This year, an estimated 40,160 women will be diagnosed with melanoma—the most dangerous cancer for women and the brilliant, caring, funny, selfless things they do that make them great. The

We hope you enjoy this special AIM newsletter celebrating Women's History Month and #WomenAgainstCancer. We honor those who have lost the battle and those who are winning; those who are fighting as oncologists and those who are fighting as patients, and everything they can do to save someone. Bottom line: Everyone can be part of the solution.



Women Against Melanoma

erous type of skin cancer—and 2,240 will die of the disease. This March, we're celebrating things we miss when they're lost too soon.

womenagainstmelanoma. Read about all sorts of women in melanoma: Those who have e who are fighting as patients; those who have lost someone and those who are doing We are all part of the cure. Join us.

# A Mother's Love Shines Light on Melanoma Treatment, Cure

by Vallerie Malkin

It wasn't right that Charlie Guild lost her battle with melanoma at 26. But in terms of the positive impact her story would have on the melanoma community, she had the right mother.

What stunned Valerie Guild from the moment her daughter was diagnosed was the lack of treatments available—and the absence of any on the horizon.

Reputable oncologists who treated melanoma existed across the country, but according to Guild, "Many told me there was a lack of collaboration that was hindering progress on fighting the disease."

Equally shocking was the painstaking and often futile process of searching for accurate information on melanoma in 2003, according to Guild. There was no comprehensive website or any authoritative source of information.

Instead of a cohesive narrative around melanoma, with structures for support, philanthropy, and research, Guild found that information was fragmented and disconnected, and the cure was a distant hope.

"It was agonizing," says Guild. "There was nothing we could do but watch her die."



*"Defeating the cancer that took my daughter's life became my life's work," says Guild.*

## **Ardent Resolve**

Guild vowed to devote the rest of her life to reversing the dismal course of melanoma. Her grief became a fierce determination to find out why melanoma lagged so far behind other cancers in terms of research and to solve those issues in order to jump start a renewed search for the cure.

"Defeating the cancer that took my daughter's life became my life's work," says Guild.

She also vowed to provide families with up-to-date and comprehensive information on melanoma—to be the resource she searched for in vain.

## **Who was Charlie Guild?**

To understand Val Guild's determination, you only have to know she is a mother who lost a daughter. But Charlie's personality also helped shape that determination.

"Charlie wanted to give back," recalls Val Guild. "She loved helping people. She hoped to have a life that would be in service to people."

Charlie was an academic achiever who studied neuroscience and Russian literature at Brown University. After college and a stint on Wall Street, she asked her employer for a transfer to the San Francisco office to be closer to family. She was considering medical school.

It was about this time that she told her mother she had a pain in her chest. After an x-ray revealed nothing unusual and the pain subsided, Charlie resumed her work, only to be hit with worse pain several months later. This time a scan was ordered, and the results were devastating.

"I will never forget that moment when the doctor told us it was Stage IV melanoma," Val said. Soon they learned just how bad the prognosis was: Viable treatment options were non-existent, and late-stage melanoma was nearly always a death sentence.

The diagnosis was devastating for everyone in the family, and of course earth-shattering for Charlie herself. "Charlie was in love with her life," Guild says. "She was intellectually fearless, but she was not fearless about dying. None of us is, I expect."

Charlie announced that she would choose to live the remainder of her life focused on the present, while her family focused on how they were going to manage her treatment. Her choice turned out to be a blessing.

"Charlie lived the remaining months of her extraordinary life on her terms, something we continue to be grateful for," says Guild.



## **First Things First**

After her daughter's death, Guild created the Charlie Guild Foundation, which would later become AIM at Melanoma. Then she set off around the world to speak with melanoma experts, asking them point-blank what was needed to propel their research.

Surprisingly, she heard one statement over and over again: We need fresh frozen primary tumor tissue; we need a critical mass of it, from a variety of patients; we need the patient data; and we need to collaborate on the research.

But they also told her collecting fresh-frozen primary tissue was nearly impossible to accomplish, from the relatively small number of melanoma tumors removed in hospital settings, to the need for freezers and protocol in those settings, to the complicated process of getting individual research institutions to work with each other on the tissue research.

Feeling defeated before she had barely gotten started, Val recalibrated, and she allowed her penchant for problem-solving and natural calm guide her.

Guild then met with Dr. Mohammed Kashani-Sabet, a melanoma researcher working in nearby San Francisco, and it was he who suggested she pursue the creation of a fresh-frozen primary tissue bank, with multiple branches around the world. He knew how valuable it would be to research, and he realized after sitting with her for only a short time that she was the type of person who could make a tissue bank a reality, even if it took many years. What's more, he told her, he would sign on to help if she moved forward.

Guild hesitated, at least momentarily. Her background made her an odd match to create the missing link in melanoma research. She wasn't a scientist; she was a CPA. Guild and her husband owned a financial services company, and she still had two daughters to raise.

Then she thought of Charlie and said, "Yes." But she would soon find out she had a lot to learn.

# Melanoma is Different

Researchers will tell you it is the primary tumor that holds the entire genetic code. Studying primary tumor tissue—when it has been fresh-frozen and the DNA and RNA are preserved, and when there is comprehensive patient data accompanying it—is key to understanding how cancer spreads and why.

In so many cancers, this process of removing and freezing primary tumor tissue, collecting data, and then studying both has been relatively straightforward: The patient comes to the hospital for inpatient or outpatient surgery; data and consent are collected; the tumor is removed, frozen, and studied. Breakthroughs in understanding and treating breast cancer and prostate cancer, particularly, can be traced to studying fresh-frozen primary tissue.

But melanoma is challenging in so many ways, beginning with a problem absent in other cancers: Melanoma tumors are usually removed in a dermatologist's office, not in a hospital surgery setting. Because of this locational circumstance, the tumors are not frozen, critical patient data is not recorded, and the chance to study that primary tissue is forever lost.

Guild had her work cut out for her.



## Who Is In?

Val resumed her world travel schedule, meeting again with some of the same experts in the field to deal of surprise that this rather petite woman intended to solve a giant problem in melanoma research.

Soon she had gathered a handful of researchers and institutions to commit to the tissue bank. She navigated discussions and negotiations to bring the institutions into agreement on how to run this collaborative,

Months turned into years. Every step of the process took longer than she imagined and involved more

“Human tissue—and the handling of human tissue—are both highly regulated and not regulated at all, rights, and storage, just to name a few, are extremely complicated. And because we were dealing with

Guild was in uncharted territory. But she pushed on, with the support of the researchers at the tissue bank at the University of Pittsburgh, whose site was slated to open first. Kirkwood and Guild talked regularly about

Years earlier, just after Charlie’s death, they had discussed the frustrating lack of collaboration and convened an informal gathering of a relatively small group of melanoma experts to share data, discuss ideas, and plan. Many researchers already attended. Additionally, they believed researchers would benefit from interacting

Guild proposed that she host just such a meeting and that Dr. Kirkwood be her co-chair. He agreed.

She immediately planned a date, sought grants, and invited 25 of the world’s leading experts in melanoma





discuss her goal of creating a global tissue bank. There was extreme interest, of course, and a good

formed the initiative the International Melanoma Tissue Bank Consortium (IMTBC) and began a global tissue repository.

detail—and attorneys—than she ever thought possible.

” Guild noted. “The legalities surrounding things like consent of the patient, intellectual property institutions in different states and different countries, the complications multiplied exponentially.”

bank sites, one of whom was Dr. John M. Kirkwood, M.D., at UPMC Hillman Cancer Center at the IMTBC and melanoma, and from these conversations, a new project was conceived.

communication among the world’s melanoma experts. They both believed there was a need for an collaboration—a meeting above and beyond the formal, presentation-style conferences that meeting informally with pharmaceutical companies, and vice-versa.

oma to discuss how they could move the needle on the search for the cure.

***"The primary tumor holds the entire genetic code. To understand and conquer melanoma—to decipher the code—we must study primary tumor tissue. To study primary tissue, we must bank it."***

Mohammed Kashani-Sabet, M.D.  
Director,  
Center for Melanoma Research and Treatment,  
CPMC



## **But There Was More For Her To Do**

Val Guild's vision was nowhere near complete. While research to end the disease was her number one goal, she also knew she had to solve the education and resource issue that so affected her family's quest for information while her daughter, Charlie, was ill.

Guild wanted to offer patients and families one place to go when they were diagnosed, a website that was comprehensive, up-to-date, and accurate. She wanted to create the website that she sought—in vain—when Charlie was diagnosed. "I remember thinking that it certainly would help if information and resources could be pulled under one roof," says Guild. "And I was determined to create just that."

In 2009 the AIM at Melanoma website, a hub of informational, educational, and advocacy resources for melanoma patients and their families, debuted to the public. The site has been redesigned three times over the years, including just recently, each time adding more and more resources that benefit the melanoma community. Indeed, the website is widely considered the most comprehensive melanoma site, with an average of 52,000 visits every month. As was Val Guild's goal, people visit the site to find the kind of information that was not available when she needed it the most, after her own daughter's diagnosis.

# Finally, an Announcement

Meanwhile, the tissue bank discussions, negotiations, and challenges continued. As Dr. Kashani-Sabet predicted, it took many years to convince institutions to give up their IP rights; to standardize patient data collection; to share data; to create the legal framework around the tissue banking concept.

But just over 15 years after her first “world tour” asking researchers what they needed to battle melanoma—on April 5, 2019, what would have been Charlie’s 42nd birthday—AIM at Melanoma issued a press release announcing the grand opening of the first branch of the International Tissue Bank Consortium under the watchful eye of Dr. John Kirkwood, at the University of Pittsburgh Medical Center.

On September 9, 2019, the second branch of IMTBC opened at CPMC San Francisco, with Dr. Kashani-Sabet at the helm, and Oregon Health & Sciences University opened shortly thereafter. AIM just announced the opening of the branch at Northwestern University. Two Australian branches should open shortly.

A singular achievement that will have remarkable results in the long term for melanoma patients, the IMTBC is the first collaborative fresh-frozen primary tissue bank for melanoma in the world, enabling the study of fully annotated fresh primary tissue that is key to understanding the genetic codes of the disease.

*“It is remarkable to me how motivated people are when they have this disease to fight it, as well as how willing they are to give back and to support AIM in finding the cure,” says Guild.*

With four U.S. locations and two international sites, the IMTBC is unique in its critical-mass approach; the goal is to collect 500 primary tumors within two years, and researchers from anywhere in the world may apply to study the tissue or data or both.

## Making Connections

Through her work, Guild has met countless melanoma patients, survivors, and families. For Guild, the connections provide a sense of renewal and even more purpose for continuing her work. For those she meets, the connections provide myriad ways to get involved.

Some survivors and families have testified before their local legislators to induce lawmakers to ban tanning bed use for minors—another of AIM’s major objectives that has contributed to bans in 19 states. Others coordinate or volunteer at AIM’s fundraising walks across the country. Still others take AIM’s prevention and early detection messages to their own communities. All want to help eradicate the disease.


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## **A Marriage of Heart and Science**

Charlie Guild's story anchors the foundation and infuses every aspect of the work of the AIM team. The n desire to see the disease cured. One of those employees is her oldest daughter, Sam, who gave up her ca By doing something positive with their loss, the Guilds have honored Charlie's desire to give back in the n "I know Charlie would be proud of this work and AIM's accomplishments," says Guild. "She would love wh But this mother is not ready to rest.

Last year, the U.S. saw an estimated 96,480 new cases of melanoma and 7,230 deaths from the disease. incidence rate continues to climb.

"There is much more work to be done," Guild says. 

**2020**

**100,350 NEW  
MELANOMAS  
WILL BE  
DIAGNOSED  
IN THE U.S.**

*"I know Charlie would be proud of this work and AIM's accomplishments," says Guild. "She would love what AIM has done for the melanoma community."*

on-profit has grown to include seven employees, all of whom share Val Guild's can-do attitude and her career as a corporate attorney to work for AIM.

most meaningful way possible.

at AIM has done for the melanoma community."

While the number of deaths is decreasing due to giant strides in research in the last few years, the

**60,190 MEN  
WILL BE  
DIAGNOSED  
WITH  
MELANOMA  
IN THE U.S.**

**40,160 WOMEN  
WILL BE  
DIAGNOSED  
WITH  
MELANOMA IN  
THE U.S.**



## **ALICE & RAMONA: A MELANOMA STORY OF SISTERS, LOVE, & HEALING**

by Vallerie Malkin

In her mind and heart, Alice Klunck's sister will always be a teenager.

Alice was just 12 years old when her 18-year-old sister, Ramona ("Mona") Harris was diagnosed with melanoma. It was 1987, when girls slathered themselves with baby oil and iodine, lying on silver foil blankets that trapped the sun's rays so they could be darker.

Tanning booths were all the rage, too: You climbed into a long, rectangular, coffin-like "bed," closing the lid over yourself for 30 minutes and emerged brown as a berry. Girls who were light or freckled emerged with scarlet sunburns.



The word was that in half the time, you'd be twice as tan and much safer using a tanning bed. Those words turned out to be true in terms of getting darker, but tanning beds are not safe at all, and research indicates that indoor tanning may cause upwards of 400,000 cases of skin cancer and 6,000 cases of melanoma each year.

Mona had probably been in a tanning bed only three or four times in her entire life, recalls Alice, who is now 44. Like most teenage girls, Mona labored to make her fair skin darker for events or sometimes just for fun.

Alice hadn't been interested in all that. She liked to play sports: volleyball, softball, and basketball. She was Mona's "bratty younger sister," but Alice idolized her: "Mona was everything to me," says Alice.

*Alice didn't know that melanoma is one of the most lethal cancers to have. "It was the 80s," recalls Alice, "I thought it was 'just skin cancer,' and you don't die from that."*

Mona had a family who loved her, a boyfriend she adored, and lots of friends. Mona was enrolled in community college, scheduled to start in September.

Mona would not be able to finish out the semester at college because soon after graduation, melanoma darkened her doorstep and tipped her family's life upside down.

## **TEENAGER, INTERRUPTED**

In April of 1987, Mona discovered a mole on her lower calf when she nicked it while shaving her legs.

"It didn't look good," recalls Alice. When the mole grew back rather quickly, Mona's



mother was alarmed and took her to a dermatologist.

After Mona's prom, she saw a general surgeon at a local hospital in Dallas, near the family's home.

The surgeon removed a banana-sized slice of tissue from Mona's calf. Alice says her sister was small and thin to begin with, and a lot of muscle mass was extracted, shrinking the leg considerably right before Mona's high school graduation in June. Mona and her parents were told she had melanoma.

Mona was referred to the University of Texas MD Anderson Cancer Center in Houston in the fall for another surgery to have the margins removed and her lymph nodes biopsied. Mona and her parents, Larry and Becky

Harris, were told that her prognosis was grim.

Alice didn't know that melanoma is one of the most lethal cancers to have. "It was the 80s," recalls Alice, "I thought it was 'just skin cancer,' and you don't die from that."

Doctors told Mona and her parents that the melanoma had spread to her brain and that she did not have long to live.

Alice's parents shielded Alice from the news, but Mona's boyfriend Greg Hooker, was in the know. "Mona lived for the boyfriend," says Alice. Upon learning the bad news, Greg proposed to Mona in November.





Alice doesn't fault her parents in the least for shielding her; she knows they were doing what they thought was best at the time. But these days Alice does tend to be doubtful that she is being told the whole truth when people tell her things in general.

Adds Alice: "I look at it now and think it's a good thing they sheltered me." Alice was able to get through her school and activities that year without falling behind. The way things were presented to her, her sister was recuperating, not terminally ill.

"My parents kept me from going through the experience," says Alice. "If other adults understood the gravity, they didn't present it to me. You could say I wasn't able to go through the trauma, and I can tell that has impacted my life."

In an attempt to eradicate the melanoma, Mona underwent treatment of chemotherapy and radiation at MD Anderson. It was about a 4.5-hour drive from Red Oak, where the Harris family lived, to Houston. Mona lost all of her hair.

Mona's mother took leave to be with her daughter full-time in the hospital. Mona's dad continued to work, visiting his daughter in the hospital whenever he could. During the school year, he shuttled Alice to the airport some weekends to see her mother and sister and sometimes Greg or a family friend would pick her up from the airport and bring her home so she could be back to school Monday.

According to Alice, the American Cancer Society helped the family with financial support for travel and hotels, which the family was grateful for.



When they determined that chemo and radiation weren't working, doctors referred her for a clinical trial at the University of California, Los Angeles (UCLA) Jonsson Comprehensive Cancer Center.

Recalls Alice: "I thought, 'Good, Mona's going to California to get well.'" Clinical trials can be effective in some cases and for some people. More importantly, future patients benefit from what is learned in each clinical trial.

Treatments were not successful for Mona, so they were stopped, and doctors scheduled a third surgery in the fall of 1988 when they would operate on the cancer that had spread to Mona's brain.

Alice began to understand that something serious was happening to her sister when she overheard a conversation her parents were having with the brain surgeon in the hospital in advance of the surgery.

Alice with AIM co-founder, Jean Schlipmann



*"My hope is that some of the clinical trials they did at UCLA are helping somebody with melanoma now so that her death wasn't in vain," says Alice.*

The third surgery took an entire day, and it was brutal: "She was cut and stapled from ear to ear. The entire family was there at the hospital. It was a really fun time in everyone's life," says Alice, sarcastically.

Doctors told Mona's mother and father they could not do anything more for Mona, so about a month after surgery they told her parents to bring her home. While there was no brain damage, Mona suffered extreme light- and sound-sensitivity, though it eventually subsided.

Mona passed away at home a few months later, on Christmas Day, at the age of 19.

## **LIFE AFTER MONA**

Mona's death was a blow that the teenaged Alice was unable to process, and one she has not gotten over. But like most people who have faced devastating losses, Alice found ways to cope, not the least of which is charitable work: a powerful antidote to unimaginable grief, as it turns out.

"My hope is that some of the clinical trials they did at UCLA are helping somebody with melanoma now so that her death wasn't in vain," says Alice.

After her death, Mona was the honoree of donations to the Cancer Research Society, which contributed funds to a new laboratory building at the Science Park-Research Division of M.D. Anderson Cancer Center. The new building expanded on the molecular biology program at the Research Division, where scientists are investigating causes and prevention of cancer. Mona's death left a terrible void in Alice's life—and some confusion. Still haunted by thoughts of her sister's life interrupted, in 2010, Alice Googled "melanoma" and the results of the search turned up AIM at Melanoma's website. Discovering AIM would be the beginning of a beautiful friendship and it would change the course of Alice's own life.

Alice decided to participate in one of AIM's walks to raise money for and awareness of melanoma. AIM Walks, now called Steps Against Melanoma, happen in cities all over the country, from Dallas to Portland to Pittsburgh.

Alice told no one in her family that she was attending the walk. Perhaps this links back to how she was kept in the dark about her sister's prognosis when she was young, or perhaps she had unfinished business with her older sister, but she wanted her first experience to be private.

At that time, the Dallas walk was still being organized by AIM co-founder Jean Schlipmann, who had lost her husband of 16 years to melanoma while he was in his early 40s. Jean served as director of AIM Walks and Events until early 2019.

“My first walk was emotional. I didn’t tell anyone I was doing it because this was something I wanted to deal with by myself,” explains Alice.

Alice says she took great comfort in being surrounded by people who understood what she had been through. The feeling of being understood brought her back to the event the following year. Her husband had a work conflict and couldn’t attend, so again she attended alone: “That was fine; I still wanted it to be about me and Mona.”

## LETTING PEOPLE IN

In 2015, Alice talked to Jean about the feeling that she was apart from the walks group-at-large because she attended without any family, and was not walking with a live survivor. With Jean’s encouragement, she told her mother what she had been up to, and her mother said, “Okay, I’m going with you.” Alice recalls feeling a bit uneasy: “It was hard to let other people in,” she explains.

But she did. Alice invited her mother-in-law, her best friend and the friend’s son, and Alice’s daughter, 9-year-old Avery.

Alice had another reason for her reluctance to involve the family: “I knew how I felt the first year and I was worried my mother would be a wreck. She still cries about Mona, like many of us.”

But what happened when Alice introduced other people to the walks was nothing short of miraculous. That year, Alice had reconnected through Facebook with her sister’s fiancé, Greg, who since then had been married, had children, was divorced, and became a grandfather.

Greg had been like a brother to her – he and Mona had been together for three years – so losing Mona meant losing him, too: “It was a double loss,” says Alice. “So reconnecting with him was extremely therapeutic and emotional.”

After Mona’s death, her parents returned all of the jewelry Greg had given her, and he had the rings melted down into a horseshoe nugget ring that he wears to this day, along with the diamond earring Mona had given him.

Alice was delighted that Greg wanted to attend the walk, and nervous because she worried that seeing him would be too much for her mother. She decided not to tell her mother and just let things fall as they may.

When Greg showed up, he and Becky embraced. They had not seen each other in 27 years – since Mona’s funeral.



Alice with Mona’s fiancé Greg Hooker

As they reached the finish line, they both cried, Alice remembers, and Jean captured the moment on film with her camera.

It was then that Alice recognized what had eluded her: “Things were starting to materialize and I thought, ‘Okay, Mona’s not just a ghost, but someone we’re actively talking about and it feels like she’s present.’”

Suddenly Alice realized that this was the missing piece: She needed Mona’s light to keep flickering, and including the people who knew her in the walk did just that.

## **PROTECTING TEENAGE GIRLS LIKE MONA**

“If you lived in the 80s and you were a girl, tanning is kind of what you did,” says Alice. But now Alice is on a mission to convince teenage girls that this is a dumb and dangerous idea.

Personally, Alice didn’t care much about tanning herself and was teased for being so pale. Now she’s proud that she has taken care of her skin: “At least I don’t have wrinkles!” she laughs.

When girls talk to her about tanning-bed tanning, Alice offers a quick and pointed retort: “Do you not feel it’s a coffin?”

“I’ve spent most of my time trying to help teenage girls,” says Alice. Now that she has one – in fact, Avery is 13, the same age Alice was when Mona passed from melanoma (and she shares the middle name “Dian” with her aunt) – Alice is even more adamant about sun protection.

Alice goes right to the punch with the girls: “You may be tan now, but when you’re lying in your casket, you’re going to be pale.” Macabre? Sure. Truthful? Absolutely.



**Women who tan indoors before they turn 30 are 6 times more likely to develop melanoma, the deadliest skin cancer.**

## WALKING THE WALKS

At the 2015 AIM walk in Dallas, Alice spoke briefly about her sister. Jean had advised her: “Talk about her, not the disease.” Alice says it is hard to separate them, and that’s one of the tragedies of losing someone to an illness. It is also a big part of doing charity work in memory of somebody lost to melanoma. But Alice thinks of future melanoma victims who might become survivors because of the funds she and her teams have raised, and this keeps her going.

In 2017 Alice learned the Dallas walk would not come around that year because Jean was retiring. For Alice, it was like losing her sister all over again to think of not being able to attend the walk. So Alice decided to take up the mantle after Jean left.

The following year, she and Jean put the event on together. Alice tried to personalize the event and incorporated painted rocks into the festivities. One rock said, “You’re a warrior.” Another would have a different saying or a survivor’s name. Alice invited participants to take a rock home to remember the experience.

Usually, planes would take off as everyone started walking, but that year Alice let a speaker talk too long and at the end of the ceremonies, when roll call took place, planes started taking off. They had to pause to wait for the sound of plane engines to subside.

When the walk started and Alice was able to talk to Jean, she asked why she had never noticed the planes taking off at Dallas Love Field before.



In 14 years, Jean had figured out the timeline of the plane departures and had planned the opening ceremonies around them. That’s why she was most adamant about this one piece of advice: “Stay on time.”

“I feel very fortunate that I got that first year with Jean, who was a huge help, and then I figured out the rest,” says Alice. There were 288 participants (including Alice’s husband) in 2018 and they raised \$50,000.

The following year, in 2019, the Dallas walk had 30 volunteers and 407 participants. Usually, Alice’s whole family ends up working the event—everything from collecting registration money to giving away T-shirts to fundraising participants who haven’t already decided to make their own. They raised more than \$30,000 for melanoma research that year.

Alice’s goal for the 2020 walk is to raise \$40,000: “Preparations are in full swing for this year’s walk, which will take place May 2,” says Alice. Alice has her own photography business and is busy but she continues to make time for the walk and will do so until it feels like the right time to hand the baton to someone else.

Alice has gotten a lot out of her work with AIM on Steps Against Melanoma. Through the walks, she has reconnected with old friends who were like family members. The walks keep her sister’s memory alive and flickering brightly each year: “This is an outlet and it has brought my family together to be able to have conversations about Mona.”

No matter how many people Alice enlists to participate in the walks, each year’s walk continues to be a private moment between Alice and the sister she loved. “When they read the names of the deceased,” she said, “they go in order from youngest to oldest. Each year I pray that no one comes before my sister. When I hear her name first, I think, ‘Thank God.’”




To help Alice raise money in Mona's memory, click [HERE](#).

## WHAT MIGHT HAVE BEEN

This summer Alice will be 45 years old. Mona, if she were still alive, would be 51 years old. Alice wonders what kind of a life Mona would have had and what kind of a relationship they would have had now. When thinking about her sister, Alice's emotions can move quickly from regret and sadness, to fondness, inspiration, and accomplishment. Mona's memory shines brightly for Alice, and she is proud of all the research that can be done through the funds raised at the walks. That research will prevent the deaths of beautiful teenagers like Mona in the future—and maybe even lead to a cure.

"I hope I see that in my lifetime," says Alice.

What does Alice think her older sister would think of her bratty teenaged sister now? "I hope she would be proud," says Alice. 

AIM AT MELANOMA PRESENTS:

# what melanoma patients need to know about coronavirus (COVID-19)

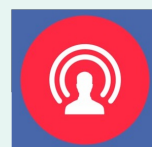
HOSTED BY MELISSA WILSON, PA-C, MPAS  
AIM AT MELANOMA'S ASK A MEDICAL EXPERT

Advice for melanoma patients, survivors, and caregivers on who's most at risk for COVID-19 and what you can do to stay healthy.

- Are melanoma patients at risk?
- Should I cancel my treatment or follow-up appointments?
- What should I do if I have symptoms?
- What if a family member develops symptoms?
- Should melanoma patients (and survivors) avoid public transportation and events?
- Are there ways to keep your immune system strong?
- Live Demo: how to correctly wash/sanitize your hands

**A SPECIAL  
FACEBOOK LIVE  
EVENT**

**WEDNESDAY  
MARCH 18  
7 pm (EST)**



**facebook**

<https://www.facebook.com/AlMatMelanoma/>



*"I know many people aren't as lucky with their melanoma diagnosis, so I want to spread awareness in honor of them as well."*

## **Natural Skin Rocks**

**Whittney, Age 32  
Melanoma Survivor**

On July 25th, 2018, I finally gave myself the push to go to my doctor after months of concern about a spot that I noticed on my back that had a mixed brown and black color. I had a punch biopsy to remove the spot, requiring a few stitches. A few days later, my doctor called to tell me it was melanoma. I had just turned 32, and my son was 18 months old. Why me? Why now? Why the one type of skin cancer that can spread internally and kill you? People die from this cancer! I was so upset and scared. My immediate thoughts were solely on my husband, my son, and my family. This can't be happening, not now.



Fast forward to Aug 10th. My husband was right by my side--his strength and support through all of this still amazes me--but I can't explain the gut punch when we left early that morning for surgery and I kissed my sweet son goodbye. I was so scared. The surgery was to remove a larger amount of tissue from my back as well as a sentinel lymph node biopsy. It works like this: Prior to going into surgery I was injected with a radioactive dye at my melanoma site, then a machine follows the trace of the dye which traces the first lymph nodes the cancer would likely spread to. It ended up in my groin area, as well as my armpit. I had lymph nodes removed in both areas during my surgery as well as the larger area of tissue on my back. I was so thankful to finally get home that evening and kiss my sweet baby boy. I was in a lot of pain and thankful the surgery was over, but I still spent the next days in fear, shedding many tears and grasping onto the little bit of hope that would cross my mind, waiting for the results.


On Aug 15th I received the call from my surgeon and dropped to my knees as she exclaimed, "It's all clear, everything, no traces of cancer!" My surgeon and all the doctors and nurses I encountered were all truly amazing and I'm beyond thankful for their compassion and knowledge, and the science behind it all.

It's hard to explain all the ways this has affected my life, and I still struggle with trying to get over things such as the fear and anxiety about not only my health but my family's health. It has crushed me more than I could imagine. Online forums just add more fear and anxiety, so I tend to stay away from them; however, what has helped me is



talking to friends and family, who have been amazing through this journey and incredibly supportive. They have asked questions and many have had skin checks and that makes me realize that although my experience was terrifying for me and my family, if I can help someone go get checked and find something sooner than I did and prevent someone else from going through what I did...that is what I want and need to do!

I know many people aren't as lucky with their melanoma diagnosis, so I want to spread awareness in honor of them as well. I haven't been in a tanning bed since I was 21 years old and I will never ever again think a tan is any kind of healthy or makes me look "pretty." I cover up with sunscreen daily and continue to take extra precautions anytime I'm outside, with sunglasses, hats, more clothing and extra sunscreen. I now see a dermatologist every three months and will see one regularly for the rest of my life, which I am happy to do!

I have had spots removed and biopsied each appointment so far, and waiting for the results cripples me every time. But thankfully all results have come back clear! Early detection is key to survival, because melanoma is most treatable when found early. Don't wait! Get checked regularly, and the second you notice something irregular, see your doctor. Embrace your natural skin color; a tan and sun are not worth your life!! You only get one skin, protect it! Life can change in an instant, so enjoy each day, each moment, love harder, laugh louder and don't sweat the small stuff. 

**BECOME AN AGENT OF  
CHANGE AND HELP  
PREVENT ANOTHER  
PERSON FROM BECOMING  
A MELANOMA STATISTIC.**

**[WWW.NATURALSKINROCKS.ORG](http://WWW.NATURALSKINROCKS.ORG)**

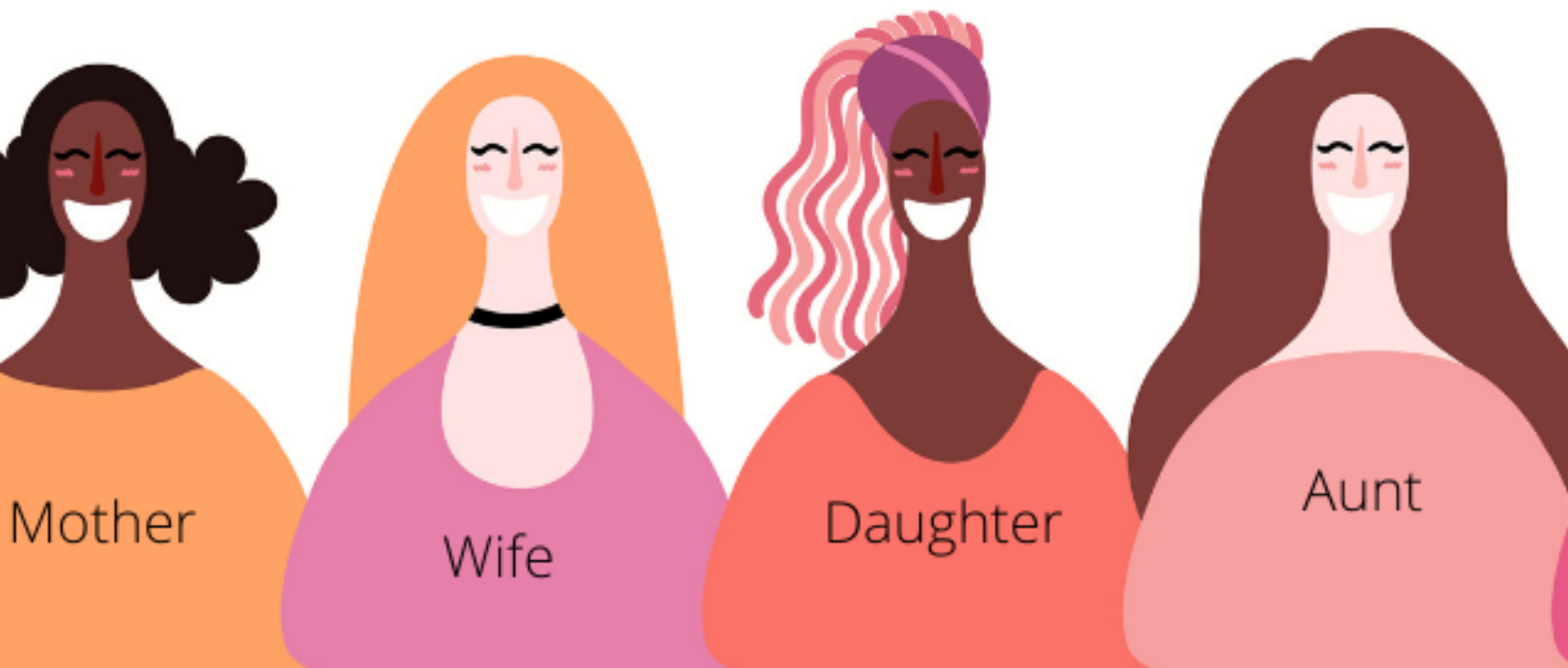
# **In 2020, it is estimated that there will be 100,350 new cases of melanoma in the U.S.**

When you register to walk and commit to raising funds, you give hope to survivors as they battle melanoma. Form a team, walk with a friend, or join an existing Steps Against Melanoma team. But definitely join an AIM Steps Against Melanoma Walk in 2020. We need you!

Check with your company as they may participate in a matching gift program that can help double your fundraising total.

## **Virtual Walkers**

If you can't walk but would still like to participate by raising money, you can register as a Virtual Walker. You will have access to all of our fundraising tools and tips.



## 2020 Walk Schedule

Virginia Beach, VA - 04/11

Galveston, TX - 04/18

Charleston, WV - 04/18

Dallas, TX - 05/02

Tampa, FL - 05/02

Portland, OR - 05/02

Pittsburgh, PA - 05/09

Salt Lake City, UT - 05/09

Las Vegas, NV - 05/16

Laguna Niguel, CA - 05/17

Eureka, IL / Hoffman - 06/06

Nashville, TN - 08/22

Bay Area, CA - 09/12

Los Angeles, CA - 09/13

Springfield, MO - 9/19

Houston, TX - 09/19

Louisville, KY - 09/26

KDB Milford - 10/11

## DID YOU KNOW?

**INCIDENCE RATES ARE HIGHER IN WOMEN THAN IN MEN BEFORE THE AGE OF 50, BUT BY AGE 65, RATES IN MEN DOUBLE THOSE IN WOMEN, AND BY AGE 80 THEY ARE TRIPLE**





DONATE  
\$50 AND  
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THIS TEE  
SHIRT

Our goal is to end melanoma in our lifetime. The way to achieve this goal is through research. Until the number of deaths from melanoma is zero, we will not stop. Everyone can be part of the solution. We are all part of the cure.

**The end of melanoma  
begins with you.**

I was first diagnosed with Stage III melanoma when I was 22 years old. I was a high school and college cheerleader, and I will never forget having to be tan in order to cheer at games. In college, all team members received free tanning, and it was expected that we go, especially when you had skin as fair as mine.

At the time of my first diagnosis, I had just graduated college and was waiting for my now husband to finish up graduate school. After 5 years of doctor visits and skin checks every three to six months, I "graduated" from the cancer institute since the likeliness of my melanoma forming again was incredibly low.

Fast-forward to eight years after from my original Stage III diagnosis, I started to develop vitiligo on my back, and all of my eyelashes and eyebrow hair turned white. I then developed a cough. It turns out I had a tumor in my lung. I had to have my lower left lung removed in order to get the tumor out. Once the tumor was tested, it turned out to be melanoma, making it Stage IV since it had metastasized from my original melanoma to my lung.

The first time I was diagnosed, I did not have many friends who really understood the seriousness of melanoma, nor could I even talk about it due to the emotional toll it took. This time around I talk openly (for the most part) about it because I have found it helps me for others to understand more about melanoma. I am also able to help raise awareness and important funds needed so a cure can hopefully be discovered.

I am so lucky to have such a huge support system, which has been a key in my recovery. My husband, parents, family, and friends have made a world of difference in helping me stay emotionally strong. If I need something, I know I can just ask, and they will help me find the answers. I know not everyone has this, and I feel so lucky I have such a huge support network. I am also taking advantage of all the great resources my doctor has offered, such as counseling and classes about healthy eating, and would highly recommend others to do the same. I have realized it is okay to accept help from others because it helps them too.

One year later after battling tumors, I am now onto my fourth type of treatment, and I finally had a clear scan! I am so incredibly grateful to all the scientists, doctors, donors, and everyone else involved in the never-ending battle to find a cure for this vicious disease.

**Mindi**  
Sherwood, Oregon



Mindi (left)  
Stage IV Melanoma Survivor



## **WIM: Emphasizing the Whole Patient and the Whole Physician**

by Vallerie Malkin

In August of 2017, AIM at Melanoma hosted the inaugural Women in Melanoma Initiative in Leesburg, Virginia. Twenty-five female oncologists from an array of notable institutions across the U.S. gathered for a weekend conference like none other.

Organized by AIM President Valerie Guild and AIM Executive Director Samantha Guild, the conference has continued each year since 2017, and the planning is in full swing for 2020.



The initiative emphasizes both patient-centric and physician-centric cross-disciplinary topics that are not typically a major focus at many oncology meetings. These varied subjects include the fertility-related side effects of new immunotherapies and targeted therapies; whole-patient care; obstacles to academic advancement for women; and the use of social media by oncologists.

“WIM presents care-based issues with the goal of improving the patient experience,” says WIM attendee April Salama, M.D., Associate Professor of Medicine at Duke University. “The topics are patient-centric.” Salama is a medical oncologist focusing solely on the treatment of cutaneous malignancies, in particular melanoma.

The meetings are also physician-centric—specifically female physician-centric. Yana Najjar, M.D., an Assistant Professor of Medicine at University of Pittsburgh School of Medicine, UPMC-Hillman Cancer Center, noted that she appreciates WIM because it allows her to connect with women who are more senior than herself, as well as those who are just starting in the field: “There is a very empowering community at the conference,” she says.

The weekend kicks off with a dinner on Friday night. Saturday morning there is breakfast and stage-setting remarks by Valerie Guild, and then the mostly women panelists conduct their sessions. Panelists may be the oncologists themselves or other guest speakers. They break for lunch and then continue with more sessions. After the last presentation, Guild ends with comments on lessons learned, and then there is a dinner. The event culminates in a brunch on Sunday morning.

The WIM schedule intentionally offers time during the weekend’s meals for the attendees to network, plan research collaboration, and expand upon the day’s patient-care topics—and the oncologists make keen use of the time.

“Doctors don’t always get the opportunities to have these kinds of discussions; the demands of the work-day just don’t allow it,” says Samantha Guild. “Now that so many more women are becoming doctors and melanoma-focused women oncologists are increasing in number, it’s good to offer that support.”

*"Doctors don't always get the opportunities to have these kinds of discussions; the demands of the work-day just don't allow it. Now that so many more women are becoming doctors and melanoma-focused women oncologists are increasing in number, it's good to offer that support."  
Samantha Guild, AIM at Melanoma Foundation*

## Improving Patient Care is the Goal

To Najjar, WIM has been inspirational and informative, combining science and communication, which results in a whole-patient approach to caregiving that she and other doctors are seeking when they attend the conference. She loves getting outside of the clinic and delving into issues that she doesn't have time for during her workday—especially issues that improve patient care.

"It's an enormous privilege to do this work, and first and foremost, to take care of these patients," Najjar says.

Back in the office, Najjar employs some of the lessons about

doctor-patient communication that she learned through role-playing exercises at WIM: "I always try to remember not to use jargon terms," she says, noting that this exercise solidified always remembering that patients simply don't understand medical jargon and it's confusing to them when physicians use it. "I also try to follow this guideline that I learned at WIM: After giving the patient two facts, I pause and give them time to digest what they have heard."

"A huge part of doing this job well is communication," says Najjar. Salama, too, draws on role-playing exercises from WIM when seeing patients. With

survivorship strong, she explains, doctors need to understand the mindset of their patients and to be mindful of the unique concerns of survivors. "Through the exercises, I was able to experience the medical interaction from the other side—the patient side—and this turned out to be invaluable and a tool I use in my daily practice," she explains.

The WIM meetings, explains Salama, are forward-thinking and ahead of the curve in terms of their focus on survivorship, long-term outcomes, quality of care, and wellness.



# Supporting Women Oncologists, Supporting Each Other

Najjar's interest in medicine began when she was a child and liked playing with a stethoscope. People would ask her, "Are you playing nurse?" and she would always reply, "No, I'm playing doctor."

Like so many of the WIM attendees, she was drawn to the complexity of oncology—both the complexity of caring for oncology patients and the complexity of the medicine. And WIM is a perfect place to focus on her passion with others who share it.

Najjar recalls attending her first WIM meeting—incidentally the day after she became a faculty member—and how special it was to be able to put real faces to the names of well-known women whose publications she had read. "We were in this beautiful setting, and it was really wonderful to meet everybody," she recalls.

She's attended every WIM session thus far and brings a passion to the forum as well as her own expertise: In 2018 Najjar received a Department of Defense Translational Team Science Award to study tumor immunology and the remodeling of the tumor micro-environment to benefit patients who are resistant to treatment. Based on collaborations she established at WIM, Najjar has collected data on the largest data set of uveal melanoma patients treated with immunotherapy, with these findings soon to be published, with many of the WIM attendees as co-authors.

Salama's path to medicine also started when she was young. "I have always known since high school, when my grandfather had cancer, that I wanted to be an oncologist and wanted to work in clinical research to help bring new things to the clinic for patients," says Salama. "I loved molecular biology, and I wanted to make a difference."



Yana Najjar, M.D.,  
Assistant Professor of Medicine  
University of Pittsburgh School of Medicine, UPMC-Hillman Cancer Center

*Salama agrees that research is critical for patients: “To move the needle there will need to be continued trials and research,” she says. “Getting to 100 percent survival is going to take many different approaches, but it’s something I would love to see in my lifetime.”*

Each year at WIM, Salama connects with other women who are equally interested in science and melanoma. “Women in science is one of my passions,” she says. “Only about 20%-30% percent of oncologists are women, so I think it’s really critical to support each other. And I think it’s critical to pay it forward.” She credits strong mentors for guiding her to where she is now and wants to do the same for other women.

Salama recognizes that women don’t advance at the same rate as men across oncology fields, and there continues to be a gender pay gap, but notes that endeavors like WIM can help address these disparities.

Indeed, Salama reports that connections made at this conference have resulted in publications, high profile committee

appointments, and invitations to talks at the national areas in which the support and advocacy of women is transformational.

## The Cure: Are We There Yet?

Yes, treatments are working, and yes, there are confidence in patient care until there is a cure. But there is still much of melanoma.

To that end, Najjar notes that Pittsburgh is one of the Melanoma Tissue Bank Consortium that will provide frozen primary tissue as they do critical research to find this resource so that she can help her patients in clinical

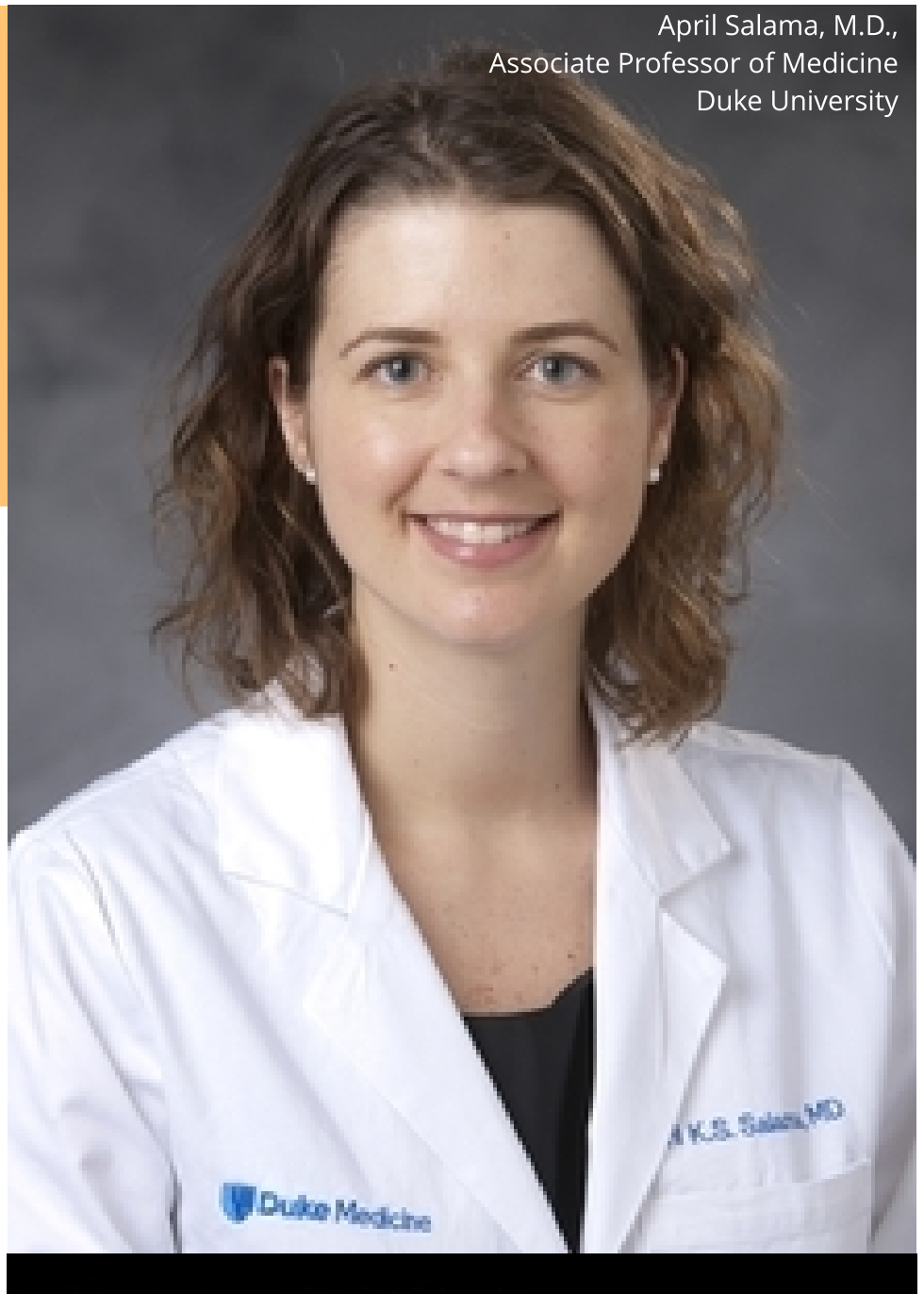
Says Najjar, “My relationship with patients is really what that I do, and every single research question I ever ask is sitting in front of me. It’s never lost on me that first and patients – everything else is secondary.”

Salama agrees that research is critical for patients: “To be continued trials and research,” she says. “Getting to take many different approaches, but it’s something I

We think all WIM attendees would agree. 



April Salama, M.D.,  
Associate Professor of Medicine  
Duke University



level for multiple attendees—all  
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ferences like WIM that aim to improve  
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and foremost my job is to take care of

To move the needle there will need to  
to 100 percent survival is going to  
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