

THE EXCLUSIVE MAGAZINE FOR, BY AND ABOUT THE RESIDENTS OF WINNETKA

WINNETKA

Living



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SPYN of Steel, Hearts of Gold



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Founding Junior Auxiliary Chairs Vivienne O'Bryan (Regina '18), Grace Sullivan (Loyola '18) and Charlotte Lane (New Trier '18) with Mas Ishida, husband of the late Susan Steel.

SPYN of Steel, Hearts of Gold

By Diane Bobis | Photos shared by Skin of Steel

"I became involved with Skin of Steel because I want to make a difference in the world."

-Vivienne O'Bryan (17)

"We lost our 'Uncle Danny Danny' to melanoma when we were little."

-Grace (17) and Jane (15) Sullivan

"I'm inspired by my dad who was diagnosed with his first of 11 melanomas when I was just five."

-Charlotte Lane (17)

For a disease often thought of as "rare," Charlotte, Vivienne, Grace and Jane, all of Winnetka, know melanoma has the power to strike any age, any gender, any ethnicity – and sometimes, all too close to home. Next month, these founding members of the Skin of Steel Junior Auxiliary will wear their hearts on their sleeves and spin their pedals to the metal to raise awareness for skin cancer prevention and raise funds for the opening of a national melanoma tissue bank repository, which will have a local branch at Northwestern University.

"This is an incredible opportunity to think globally, and act locally," says Charlotte, a junior at New Trier. One of her Auxiliary co-chairs is Vivienne, a junior at Regina Dominican and the daughter of well-respected cancer expert Pia Gargiulo O'Bryan.

"I keep hearing how much progress is being made in the area of new targeted drug discoveries, yet cancer continues to affect so many of our friends and family," says Vivienne. "We are proud to be elevating the discussion about what young people can do."

Skin of Steel (SOS) was founded in 2010 by Susan Steel of Glenview, who at the time was a five-year, stage III melanoma

survivor and mother of two. She and her board of directors all had children attending Glenbrook South High School in Glenview, and together with their teenagers, they established the ban on tanning bed usage by minors under the age of 18; first in Glenview, then in the City of Chicago, and ultimately at the state level. To date, Illinois is one of just 13 states, plus the District of Columbia, to have banned tanning bed usage by minors because of harmful exposure to UV radiation.

Shortly thereafter, SOS began to collaborate with San Francisco-based AIM at Melanoma about the creation of the first-ever national primary tissue bank for the advancement of melanoma research. AIM was founded by Valerie Guild after her own daughter, Charlie Guild, died of melanoma at age 26.

"Years from now, Susan Steel and Val Guild will be heralded for their unrelenting efforts to bring fresh primary tissue to the forefront of medical and scientific research," says Grace's father, Steve Sullivan. As current SOS Board Chair, Sullivan works alongside fellow Winnetka residents Jeanne McAtamney and Trip Lane, as well as board members from Wilmette, Glenview and Skokie to see Steel's dream of building a national tissue bank come to fruition.

To be clear, many research institutions and hospitals already have tissue banks for all types of cancer, but no one is openly collaborating and sharing the bioinformatic data on fresh, frozen, primary melanoma tissue. That is where SOS and AIM come in as an independent operation to fund the Melanoma Tissue Bank Consortium. Experts remain convinced that frozen tissue retaining both DNA and RNA will advance the genetic coding of biomarkers critical to advancing personalized medicine.

“I know that there’s a hereditary component to this and my kids are in danger. So with whatever life I have left, this is what I will do,” said Susan Steel after being honored with a Philanthropy Award from the Make it Better Foundation 2014. And she persisted in her efforts until the end.

After an 11-year “sword fight” with melanoma, Steel passed away in January 2016 knowing that the work of SOS and AIM would succeed in helping to improve outcomes for other families with melanoma. Through sheer will and determination, she survived 11 years, seven brain surgeries, seven clinical trials, and 50 trips outside of Chicago for care.

During her tenacious battle to stay one step of the disease, Steel became a beacon of hope to many other “melanoma warriors” as she traversed the country to participate in promising clinical trials. “Since 2011, there have been 11 new drugs approved for melanoma treatment,” says Sullivan. “Patients like Susan and a beloved Winnetka neighbor Jim, and so many others subjected themselves to grueling trials to stay alive and benefit medical research at the same time.”

Today Skin of Steel and its Junior Auxiliary extension of north suburban high school students remain deeply committed to Steel’s mission to advocate for sun safety, the prevention of skin cancer, and making the national melanoma tissue bank a reality. With the dedication and support of many North Shore families, they are getting very close to opening the first one or two branches. In addition to the medical research institutions at the University of Pittsburgh Medical Center, Oregon Health & Science University, and California Pacific Medical Center, Northwestern University is slated to host the fourth branch of this unprecedented open collaboration among researchers, potentially changing the landscape of melanoma on a local, national and even global scale.

“Clearly the disease can start when we are young. We think the Junior Auxiliary is an important part of getting the message out there in a positive, ‘Livestrong’ way,” says Sullivan. “A tissue bank with global potential is a lot to wrap your head around, so we want to make it easy to understand. These kids hope to raise enough money at their SPYN of Steel event in May to purchase one freezer for tissue storage that goes to -80°. Additional dollars will go toward the proper collection, freezing and annotating of tissue samples.”

What drives SOS is that the opening of the tissue bank will



Skin of Steel founder, Susan Steel, provoked revolutionary personal, behavioral and institutional change in dealing with melanoma.

result in better outcomes for patients through more effective, targeted, personalized medicine – and better overall outcomes for families. Board member Jeanne McAtamney lost her father to melanoma when he was just 52 years old.

“The tissue bank will provide us with information that we don’t have for melanoma – information that will allow doctors to personalize treatment plans for those diagnosed,” says McAtamney. “I have spent the last 18 months of my life fighting breast cancer. My treatment was straightforward and my prognosis positive, and that is largely because of the advancements we have made in understanding breast cancer. We need more research and more information to be equally successful in understanding melanoma. Our futures and our children’s futures depend on it.”

And while SOS works to further cancer research specifically in melanoma, the identification of genetic biomarkers via the tissue bank will benefit other cancer research efforts as well.

“There are so many great organizations out there raising funds for cancer research,” says Grace, Auxiliary co-chair and junior at Loyola Academy. “What motivates us to help with research in melanoma is that it is leading to discoveries in other cancer treatments affecting so many families we know and love.” An example: just this year, the melanoma drug Keytruda® was also approved for treating non-small-cell lung cancer and Hodgkin’s Lymphoma.

Trip Lane, melanoma survivor, Charlotte’s father and SOS Board Member explains: “One of the things we discuss with the Junior Auxiliary is that there are many families in town impacted by lots of other cancers, particularly breast cancer and lung cancer. The goal of the melanoma tissue bank is to further research in the area of ‘personalized medicine’ by properly freezing and annotating cancerous melanoma tissue to unlock the genetic codes lurking in cancer. This could help ALL cancers because accredited researchers will have access to the bio-informatics that can further research through genetic data.”

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The Skin Of Steel Junior Auxiliary Is Proud To Announce The 2nd Annual SPYN Of Steel

Wednesday, May 3

@Spynergy Cycling Studio, Winnetka

Ride to great music with friends for a 45-minute class to help raise sun safety awareness and build the first-ever national, collaborative melanoma tissue bank repository. Every \$15,000 raised will fund the purchase a freezer for proper tissue storage. And each additional \$2,500 raised will help collect, annotate and freeze one tissue sample to further cancer research!

*Teens ride for \$25; adults ride for \$75
For time slots and registration, please visit:
www.skinofsteel.org/spyn-steel-2017-registration*



SPYN OF STEEL

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Lane has the BAP1 gene that causes atypical melanoma: "As an 11-time survivor, I have very personal stake in the success of the tissue bank, as does my family." Lane's daughter, Charlotte, was just a kindergartner when his melanoma metastasized and spread to his lymph nodes. With surgery and aggressive chemotherapy, he has beaten the odds and is involved in research on a national level.

"After seeing first-hand how cancer affects those we love, I was inspired to take action in preventing skin cancer, especially geared towards younger generations," says Charlotte. "I hope we can educate people about melanoma and its causes, as well as teach people about our organization and the difference the tissue bank can make. It's amazing to see our community come out and support our cause." Last year's inaugural event drew over 150 riders, raising \$12,500 for melanoma research.

"This is our second year and we cannot thank Spynergy owners Tory Raith and Jen Solberg and their instructors enough for making the studio



Melanoma survivor Trip Lane, with daughter Charlotte and wife Felicia at 2016's inaugural SPYN of Steel.

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available. They are high energy," says Sullivan. The organizers are also hoping that "Grill Chasers," the food truck owned by former Winnetka residents Gary and Jami Steinberg, will return this year as a post-ride reward for participants and neighbors who see all the energy downtown.

"I love that SOS Junior Auxiliary is so student driven," says Vivienne. "As teens we sometimes think we do not have a lot of power in the world. But the more people we can educate, the more people we will protect. There is only so much any one of us can do, but together we can do a lot."

For more information about Skin of Steel, please visit www.skinofsteel.org.

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