

Eye On A Cure



Winter 2015

Greetings!

Last year was a breakthrough year for OMF. Beyond increasing fundraising almost 60% over 2013 - OMF has raised over \$500,000 for OM support and research - we've been hard at work building on our core patient support and education initiatives such as the Patient Forum, TAG and PAP, to also offer the OM community robust but capital efficient scientific programs. These valuable programs look at the 'long ball' - finding an eventual cure for ocular melanoma - while offering compelling resources for patients, caregivers and physicians in the near term.

The first building blocks of this scientific platform are stronger research initiatives, which is why we partnered with the <u>American Association of Cancer Research (AACR)</u>, the oldest and largest scientific organization in the world focused on every aspect of high quality, innovative cancer research, to offer a \$50,000 per year OM research grant. The second round of awards is being decided upon right now and we look forward to growing this in the years to come with some strategic donors who have stepped forward! OMF is also now partnering with the <u>Rare Cancer Research Foundation (RCRF)</u> to accelerate the creation of a cell line bank at the ATCC which will assist OM researchers across the globe. And these are just a few of the things we've been working on in 2014!

Our yearly Patient Retreat, held last October at the Cleveland Clinic and which you can read more about below, was the largest gathering of OM patients **ever** and we are looking to grow that to an ever bigger, better meeting in 2015. Smart partnering, the leveraging of technology (including, increasingly, social media) enables us to do more with our resources and we continue to count on you - our donors, partners and grassroots Warrior fundraisers - to make this all happen. So, thank you!

EANA Patient Retreat Largest OM Gathering Ever!

Held at the beautiful <u>Cleveland Clinic</u>, with over 200 attendees, EANA's 2014 retreat proved to be a time of connecting and learning. It also proved to be the largest gathering of ocular melanoma patients and caregivers ever!

As with past years, the retreat included an array of activities and presentations including yoga sessions in the morning and expert panel discussions throughout the day. Some highlights included:

- Peter Hovland, OMF's Medical Director, set the stage for the conference by giving an overview of ocular melanoma and the reactionary stages after initial diagnosis.
- Dr. Arun Singh, head of Cleveland Clinic's ocular oncology group, gave an informative presentation called Uveal Melanoma 101.
- OMF's first <u>Junior Investigator Award (JIA) award winner</u>, <u>Alexander Shoustari</u>, provided an update on his research on <u>Overcoming Resistance to MEK Inhibition in Advanced Uveal Melanoma</u>.
- An Art Tour of Cleveland Clinic provided reprieve and insight into the art of healing.
- Warrior Awards were presented to Laura Culbreath, Gary Fisher, Michelle Metts and Arun Singh, MD of the Cleveland Clinic.

For those of you unable to attend the EANA retreat in person, videos of each main session, including video from the past two years, can be found on <u>YouTube</u>.

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UPCOMING EVENTS



April 11, 2015

Lisa Spiers 5k Run/Walk Kilmarnock, VA

Learn More>>

Clevela



April 18, 2015 Swing for Sight Golf Tourney Napa, CA

Learn More>>



Eye Patch Day May 20, 2015



Watch us on Tube



Location Set for 2015 Retreat

The 2015 Eye Am Not Alone Retreat will be back at the <u>Cleveland Clinic</u> for a second year in a row. The Clinic, under the watchful leadership of Arun Singh, was a fantastic partner in 2014, and OMF is excited to continue this going forward and to build on the success of the 2014 retreat. For 2016, OMF is contemplating a larger meeting on the west coast.

Our Amazing Warriors

Just Go For It!

When Joanne Barlia was first diagnosed with ocular melanoma, her reaction was 100% shock. A busy mother of four, with two still at home, Joanne was involved with all the things it takes to run a home and family. Life quickly became more complicated as she began treatment. Throughout the process, Joanne wasn't exactly sure how to answer the one question her friends and family kept asking: "How can I help?"



She explained, "I decided to hold a fundraiser so I could finally answer their question. *Here's a way* you can help me."

Joanne started with a simple idea. She wanted to create a multi-event platform to reach as many of her friends and family as possible. She said, "I hoped at least one event would work for everyone." Looking back she laughs at the memory because up to that point, she'd never really organized anything of that magnitude before. Besides helping with school fundraisers, this was brand new.

Joanne hosted one event a month for six months: a walk-a-thon, a body conditioning class, a sports conditioning class, a Zumba class, a belly-dancing class, and a yoga class. She called the fundraiser "Come Exercise With Me!" Although she recommended an entrance fee of \$100 per family, she left it up to the individual to make a donation. In all, she raised an astounding \$14,275. "It felt good," she said. "The support was amazing."

Her favorite moments were having her recent college-grad son, Joseph, come to lead the sports conditioning event and having her mother (who lived an hour and a half away) attend every event...yes, even the belly-dancing!

Warrior Fundraising Advice: "Just do it!" Joanne said with a laugh. "I had no idea what I

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Eye Am Not Alone
Patient Retreat
Oct 16-18
Cleveland Clinic
Cleveland, OH

BY THE NUMBERS

12 years since founding #1 on Google for OM \$500k raised for OM 2,704 Facebook 'likes' 2,228 Forum members 13,900 Twitter followers



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was doing at the beginning....but in the end, I felt empowered and supported."

A "Silly Little Eyepatch"

"I can't believe what started with a silly little eyepatch has inspired such a response," Brendan Trimboli said when I first asked about his Warrior efforts.

Though I know Brendan's words are a reflection of his humility, there was nothing silly or little about his accomplishment on November 2014 when he ran the New York City Marathon wearing an eye patch.

Brendan's mother, Lillian Trimboli, was diagnosed with ocular melanoma when she was 26 years old. Her eye was removed, she recovered, and she had Brendan three years later. Lillian lived an active lifestyle, loved to run, and even did some cross country coaching. When Brendan was in eighth grade, the cancer came back, and she died when he was a sophomore in high school.



Brendan knew he wanted to somehow honor his mother and raise awareness for ocular melanoma, but it wasn't until he qualified for the New York City Marathon that the pieces started coming together. He explained, "Life is short, and I started thinking I've got to do this. My mom was diagnosed at age 26, the age I am now."

Once he'd made his decision he set the goal of raising \$2620 - \$10 per mile. He asked friends and family to make the donations via an online fundraising tool. He used facebook and his blog to advertise. And on November 2, 2014, he ran the race...with an eye patch.

"All I could think about was how my mom did all of this with vision in only one eye, how you have no depth perception," he said. "It honored what she did and grabbed attention for what I was doing in a subtle way."

As for the future, Brendan is directing three races in Colorado this year, and he plans to send the proceeds from at least one of them to OMF.

Warrior Fundraising Advice: "If there's something you're passionate about, try to leverage it," Brendan recommended. For him, running was the key. He also added, "Set an achievable goal, then go out and outperform your expectations."

Interested in Putting On A Warrior Event?

The <u>Warrior Fundraising Program</u> is OMF's platform to empower members of the OM community to contribute their own time, talent and treasure. We work with YOU to put on an event or do something amazing - whether it's hosting a BBQ at your home, running a 10k or hosting an awareness event at your kid's school. We can supply you with helpful instructions and best practices, plenty of giveaways (brochures, SEE A CURE sunglasses, t-shirts, anything you need), and even additional volunteers and funds to make it a success and can work alongside you to ensure it raises awareness of OM and funds for OMF research initiatives.

To learn more or to get your event planning started today, drop Holly, OMF's new Program Director, a note at holly@ocularmelanoma.org.

Expert Advice

Excerpt from "Caring for Skin Around the Eyes" by Anne Willis, LE, CME

The skin around the eyes displays expression and emotions that are an important part of our individuality. But the health of the skin surrounding the eye area is what matters when someone is diagnosed with ocular melanoma. Ensuring skin can withstand the impact of medical therapies, reduces side affects that cannot only be uncomfortable, but can impact recovery.

Skin symptoms related to medical therapies and surgeries may occur, and they include dry, scaly, flaky skin. There are several ways to reduce these side affects and to support the skin if symptoms do occur.

- 1) Start with *simpler skin care routines* and invest in deansers that heal, not products that peel.
- 2) Stay away from cleanser with moisture-stripping alcohols and sudsy sulfates, and instead use cleansers based with seed oils and pure botanical ingredient. Herbal teas can also be a healthy alternative for specifically bathing the eye area.
- 3) Increase suppleness around eye with serums based with oils of Acai, Red Raspberry, and Broccoli. These pure botanical oils are high in omega-3 fatty acids, which reduce inflammation and hydrate skin by reducing epidermal moisture loss.

Caring for the skin during medical oncology therapies is about achieving balance. The ultimate goal is to provide a holistic approach for an optimal healing environment that enhances the body and skin health, thus supporting overall well being and comfort.

Jenny Mottershead Executive Director

Juf Nottestrad

Grant Allen Co-founder, Chairman

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