



As we begin to bundle up and look towards the fast approaching holiday season, we welcome you to take a quick look at all that's been going on at OMF. From our 6th annual **Eye Am Not Alone (EANA) Patient Retreat** in Miami to our growing number of grassroots Warrior events, from the [NORD summit](#) in Washington DC to on our [ongoing work with RCRF](#), we continue to deliver support to OM patients and much needed funding for cancer research.

Thank you for allowing OMF to be a part of your journey. If there's one thing we know, it is that together we are stronger. As our OM community joins together, we share full hearts, generous thoughts, voices of awareness and a common hope to "See A Cure!"

## EANA Highlights

### 2016 Patient Retreat Showcases Medical Highlights from Bascom Palmer, MD Anderson and Thomas Jefferson University

The **2016 Eye Am Not Alone Patient Retreat** drew over 100 attendees to steamy Miami, FL for a [full three day agenda](#) of networking, socializing and medical education. The Retreat was hosted by Dr. Bill Harbour, one of the very top ocular oncologists in the world, and showcased the phenomenal Bascom Palmer and Sylvester Cancer Center staff, including Stefan Kurtenbach, one of Dr. Harbour's research fellows and the last year's OMF/AACR JIA recipient.

Saturday was a packed day taking attendees through the "101" on eye cancer, a deeper look at plaque modeling, and a [broad overview of current trials](#) punctuated by a panel including TJU's Takami Sato and MDA's Sapna Patel. Dr. Jonathan Zager of Moffitt Cancer Center overviewed the promising [current Phase III clinical trials with Delcath Systems'](#) balloon isolating system (percutaneous hepatic perfusion, or PHP) which delivers targeted chemotherapy treatment to the patient's liver.

## In This Issue

[EANA 2016](#)

[Warrior Update](#)

[NORD Summit](#)

[Prosthetic Grant Program](#)

## Quick Links

[OMF Website](#)

[OMF Facebook Page](#)

[Friends & Family FB Group](#)

[OMF YouTube Channel](#)

## UPCOMING EVENTS



### "Be the Light"

Kammerman  
Fundraiser - \$50,000  
for OM Research  
Nov. 27  
Binghamton, NY

[Learn more>](#)

#GIVINGTUESDAY

### Giving Tuesday

Nov. 29

[Learn more>](#)

## BY THE NUMBERS

13 years since founding  
#1 on Google for OM  
3,333 Facebook 'likes'  
2,577 Forum members  
7,588 Twitter followers  
115k annual web visitors



Recipients of 2016 Warrior Awards were: **Joanne Barlia**, **Lori Caperton** and **Ryan Gibson** for their herculean efforts at fundraising and driving awareness.

Thank you to ALL of the doctors, patients, caregivers and OM community members -- all the Warriors -- for making this year's retreat such a success. Next year, we'll be taking EANA to the west coast and are working on a draft agenda now in collaboration with UCSF and Stanford.



## Warrior Update

### A Warrior Looking to Honor Her Mom

**Jeanne Bernhard** of Gilbertville, PA wanted to do something to honor her mother who is a current OM Warrior and to bring awareness to this orphan disease.

Her event took on a dual platform as she organized a bake sale at her work and ran the Rock 'n Roll Half Marathon in Philadelphia. Jeanne explains, "Since the major sponsor of the half marathon is *American Association For Cancer Research*, I figured why not have a warrior out there running to help bring attention to this orphan disease?"



Jeanne's efforts raised \$1,500. Although the money was a fantastic accomplishment, Jeanne explained a bigger takeaway, "I can say we definitely brought awareness to ocular melanoma. There were people who had never heard of it. Interestingly, one of my colleagues has an aunt who moved to the United States from South Korea because she has OM. I couldn't believe it! In a company of about 250 people, two of us have family members affected by this orphan disease."

*Congratulations to Jeanne and her wonderful Warrior efforts!*



**Jeanne's co-workers spread awareness while**

### Interested in Putting On A Warrior Event?

The Warrior Fundraising Program 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 child's school. We can supply you with helpful instructions and best practices, plenty of giveaways (brochures, SEE A CURE sunglasses, t-shirts, etc.), and even additional volunteers and funds to make it a success! We can also work alongside you to ensure your event 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 Warrior Program Director, a note at [holly@ocularmelanoma.org](mailto:holly@ocularmelanoma.org).

## NORD Summit

The **Nation Organization for Rare Disease (NORD)** held their annual summit in Washington, DC on October 17-18. Over 600 attendees came to rally support, awareness, and treatment for rare diseases and both ocular melanoma and OMF were well represented!



Two presentation highlights:

### Expanded Access Program

Lucas Kempf, MD, of the FDA presented the updates to the Expanded Access program which covers "the use outside of a clinical trial of an investigational medical product." Some encouraging updates are the streamline process including a single page document for the doctor/sponsor request and a 24 hour turn-around time for emergency requests. Non-emergency requests are answered within four days of the submission. And 99.5% of requests are given the "green-light."

Learn more about the FDA Expanded Access Program [here >](#)

### New Research on Gene Editing

John Leonard, MD, of Intellia Therapeutics, gave a fascinating presentation on gene editing. Different from gene therapy, gene editing rewrites or cuts/replaces genes. The research is in infancy stage with promising success. It has the potential to transform treatment by permanently editing disease-associated genes in the body with a single treatment course. Although still in research phase, the potential for cancer treatment is great. Leonard emphasized that the largest success of gene editing, so far, has been conducted in treating the mutations in the liver.

Learn more about research at Intellia Therapeutics [here >](#)

NORD has published the presentations and keynote addresses on their [website](#).



**Marshall Sumar, MD moderates the panel on "The Crucial Role of Data in Advancing Diagnosis and Clinical Drug Development" at NORD Summit**

## OMF's Prosthetic Award Program

OMF's Prosthetic Award Program (PAP) is another way we deliver support to OM patients. This needs-based award provides supplemental coverage (in some cases, full coverage) of an ocular prosthetic. OMF has committed up to **\$10,000 per year** for individuals with evidence of financial hardship to receive financial assistance for OM-related, doctor-prescribed ocular and facial prosthetics. Anticipated awards are **\$1,000 - \$2,500 per individual**.



John, a 2016 recipient of this award says, "The PAP Grant relieved a lot of stress off an already stressful situation for me and my family. The program was easy to work with! My new prosthetic eye has made my confidence level sky rocket after my surgery!"

Find out more about PAP and OMF's other financial support programs [here >](#)

## Fall 2016 Pictures



**Jeanne Runs the Rock 'n Roll Half Marathon for her Mom!**



**Tribute to the OM Caregivers**



**EANA Registration**



**EANA Saturday Dinner - Hosted by Bascom Palmer Eye Institute**