



MELANOMA INTERNATIONAL FOUNDATION

SUMMER 2009



MIF Forum Is A HIT!



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WAWA GIRLS UPDATE

The MIF forum is the first and only fully moderated melanoma bulletin board on the world wide web. Specialists in melanoma, primarily volunteer dermatologists and oncologists, as well as Catherine Poole, President and Founder of the Melanoma International Foundation, a melanoma survivor, and patient navigator for 20 years, monitor the site regularly. After just one year of operation the forum already has over **800 registered members and thousands more who participate from the U.S. and 61 other countries.** The forum is always active and provides daily stimulating discussion, online support, education, answers to melanoma related problems and reassurance for patients, friends and family members. It's a great compliment to our phone hotline and personal e-mail response system. Check it out at www.melanomaforum.org

FORUM FEEDBACK

"Your site is a trove of information and a wonderful resource for people in this awful situation. It is clear from all the postings that the melanoma community is lucky to have such an advocate."

"I especially like reading the forums because thanks to them, I do not feel alone in this fight against the beast and I know that it is possible to live a long life. Keep up the great work and THANK YOU!"

"I scared the wits out of myself reading about and looking at pictures of melanoma on the internet, that is, until I found your website. It was the first place I got to on the internet that really did calm me down. Everyone on the blog is so kind, supportive and incredibly informative. The rest of the website is great too."

Forum Name
Melanoma: Newly Diagnosed Moderator: MIF Staff Did you just receive a melanoma diagnosis? This is the perfect moderated forum to obtain information about pathology as well as get your most important questions answered.
Melanoma Diagnosis: Stages I & II Moderator: MIF Staff This moderated forum is to support the needs of patients with stage I & II melanoma, as well as answer questions about treatment options.
Melanoma Diagnosis: Stages III & IV Moderator: MIF Staff This moderated forum is to support the needs of patients with stage III & IV melanoma, as well as to answer questions about treatment options.
Melanoma: Friends & Family Moderator: MIF Staff This moderated forum is for the friends and family of melanoma patients who are seeking answers and support.

Would you like to help our melanoma patient support programs? Here's how...

Visit www.safefromthesun.org and click "donate". Be sure to check with your company...many companies offer a "gift matching" program!



We participate - the online standard for nonprofit accountability.



Seal of Approval Partners

As part of our mission to prevent melanoma, MIF has developed our **Seal of Approval Program** for products that promote sun safe behaviors, demonstrate quality and are in accordance with our mission. The program is open to any company that chooses to apply for the seal. Products are evaluated by our board based on company supplied independent testing, product quality, and the product's reinforcement of sun safe behaviors.

SEAL OF APPROVAL PARTNERS

- Ayana Apparel
- Baby Banz
- Coolibar
- MFS Eyewear
- Raptya
- Shedrays
- Sierra Summits
- SPF Store
- Sunday Afternoons
- Sunveil
- Tilley Endurables

A number of companies have already participated in the program and become part of MIF's mission to educate others about early detection and sun safe behaviors. Be sure to visit our website at www.safefromthesun.org and click on resources to learn more about their outstanding products!



PROJECT WAWA 2010

25 to go!

After visiting an astounding 575 Wawa convenience stores and spending nearly \$3000 on coffee, hoagies and all sorts of foods, The Wawa Girls, as they have become known, have almost reached their goal of visiting all 600+ Wawas.

The five girls, Jill Fitzpatrick, Emily Koch, Andrea Sasin, Mary (Speer) Schmidt and Ann Wuetig, all friends since high school, have spent the last 2 years trekking up and down the east coast to every Wawa, bringing awareness to melanoma and honoring their friend, Maria Whitehead, who died of the disease at the age of 25. At the end of their quest, the girls will be applying for a grant from The Wawa Giving Fund as a contribution to MIF, requesting that Wawa match the amount that they have spent in their stores! To learn more about the Wawa 2010 Project visit their site at <http://wawa2010.blogspot.com/>.



MIF Kid's Bookmark Contest

MIF is sponsoring a bookmark contest to promote their sun safe practices. The contest is open to children from preschool age through 8th grade. Judging will be based on originality, design & work that reflects the mission of MIF. Copies of the winning bookmark will be distributed to the winning school and at MIF events.

Entries are to be submitted by December 31, 2009. Winners will be announced in February 2010. Please visit MIF's website www.safefromthesun.org for a copy of the contest rules.

Remember to include good sun safe practices on your bookmark!

- **Wear Protective clothing and a broad rimmed hat**
- **Apply sunscreen in addition to clothing**
- **Avoid sun exposure between 10 am & 4 pm**
- **Seek shade**
- **Avoid tanning salons**



Meet the MIF Staff

Preparing for one of our largest events of the year! Pictured below left to right, Debbie Cornelius, Lisa Newcomb, Catherine Poole, (President) and Joan Giombetti.





MIF LAUNCHES NEW EDUCATIONAL PROGRAMS

Children and adults learn about sun safety awareness!



In response to an overwhelming need for sun safety education both locally and nationally, MIF has launched a number of new programs designed to educate all ages about sun safe practices and melanoma awareness.

Our newest program, "Summer Survival" is being developed in partnership with the worldwide organization *Safe Kids*. This program will target kids attending camps throughout the summer. In an effort to begin to mainstream sun safety along with more traditional safety issues, the program features hands on stations that will promote auto, water, bike, internet and sun safe practices.

Along with the Summer Survival Program, MIF has also developed 2 programs aimed at school aged children and their families. We recently piloted our "Safe in the Sun Fun Trivia Game" with 120 second graders. The power point based game proved to be a ton of fun as well as extremely educational for the students and teachers alike.

Both this program and our "About Melanoma" Power point program are designed to be used nationally. If you would like to hear more about these programs, contact Debbie at deb@safefromthesun.org

Upcoming events

Summer Survival Camp Programs

- various locations

August 3rd

Roger Berg Memorial Golf Outing

- Lakewood, NJ

August 22nd

Wadsworth Walkathon

- Wadsworth, OH

September 12th

Elk Grove Walkathon

- Elk Grove, CA

September 15th

Dodgers Night

- Los Angeles, CA

October 10th

SAFE FROM THE SUN WALKATHON

- Tucson, AZ

April 25, 2010

SAFE FROM THE SUN WALKATHON

- Villanova, PA

To find out more about our events, visit

www.safefromthesun.org



WATERTOWN, NY 2009

Spotlight on Tucson

SAFE FROM THE SUN WALKATHON

Tucson, AZ

October 10, 2009

This walk is the result of an exciting new partnership with the Arizona Cancer Center!
BE SURE TO JOIN US!...Register online NOW at www.safefromthesun.org



WATERTOWN, NY 2009



MIF "Never Walk this Path Alone" Mug

Check out our store

Support MIF and give a gift to a loved one, a survivor or treat yourself. Check out our store at www.safefromthesun.org to see the great selection of gifts that show you care!



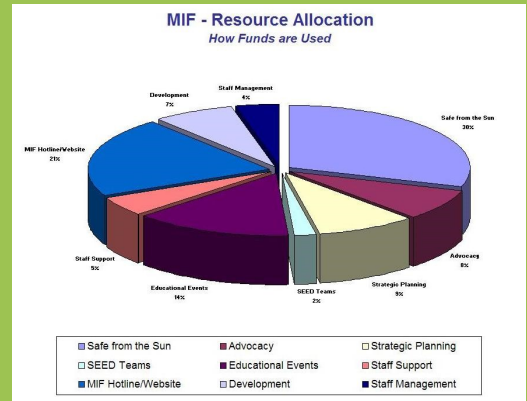
MIF Wristband



Dogwood Jewelry set



Melanoma Book



Your MIF Dollars at Work!



A Letter from the President...

Where Are We Headed with Melanoma Treatments? You Can Make a Difference!

As most in the melanoma community know, our options currently are very limited for hopeful therapies to treat metastatic melanoma. After navigating and advocating for patients for a long time, I really lean towards treatments that are the least toxic and will not damage a patient's quality of life. We have many older therapies that are highly toxic and have a low rate of return. Sadly, these treatments haven't changed much over the years and many follow the dictate that the more "aggressive and toxic" the better. I have a different mindset that since melanoma is immune responsive, in fact the less damaging treatments might prove better. At this year's American Society of Clinical Oncology, a treatment was spotlighted that had these qualities. It is the first exciting breakthrough since Sorafenib. Like Sorafenib, it is a B-raf inhibitor called PLX 4032. These small molecule inhibitors of B-Raf kinase are selective for this mutation found in 60% of melanoma tumors. Although the drug has just finished up phase 1 testing in a small group of patients in various locations, it breezed through the toxicity and dosage tolerance phase. It is on the right track for targeting therapy rather than blasting the whole body. Disease control lasting up to 14 months was reported. Regression of metastatic lesions in every site to which melanoma usually spreads occurred. Phase II trials should tell us more. Glaxo Smith Kline is now coming up with another B-raf agent and I expect we will see more. Whether there will be a durable response is not known yet, but we will be keeping close tabs on this therapy.

Ipilimumab, the anti-ctla 4 agent was revisited at ASCO as well, with investigators reporting 12 month overall survival rates over 47%. Dr. O'Day who heads the Angeles Clinic, presented the data, and said that "while this class of drugs has a fairly low response rate, the survival curves show a plateau above 30%. He added that with interleukin-2 survival is about 10%. However, the use of ipilimumab causes patients to experience auto-immune toxicity, although more manageable with steroids. Lynn Schucter, MD, who directs the melanoma program at Abramson Cancer Center noted there was a loss of a considerable number of patients from follow-up, which in turn calls for a "cautious interpretation of survival benefits." Ipi may return to compassionate use for patients in a few months. We will keep you up-to-date when that happens.

MIF helped bring some new dollars, 4 million, to melanoma research this year. Through our collaboration with Congressman Charlie Dent, the Department of Defense finally allocated congressionally directed funding to melanoma research as it has done to other disease groups. Congressman Dent has dealt personally with melanoma in his family and that is usually how dollars move to melanoma. I would like to urge all of you who have been affected by melanoma to contact your congressman or senator and tell them your stories. Insist they support more funding to the National Cancer Institute for melanoma research. The American Cancer Society also supports research from their Relay for Life revenues, but does not have melanoma on their top ten targets. Write letters, send emails, urge these wealthy funders that we no longer will accept melanoma being the forgotten cancer.

Sincerely,

Catherine Poole, MIF President & Founder