

TRUE STORY

Brown's new non-fiction recounts wife's battle. PAGE 3



TRIATHLON

McCloskey beats 125 others in inaugural race. PAGE 4



Melanoma Education Foundation Newsletter

Saving Lives Through Education

FALL 2012

http://www.skincheck.org

A TALE OF TWO CANCERS

How a pair of young women found and conquered melanoma.

BY ANNE VICKMAN

ccording to the National Cancer Institute, .6 percent of those diag-Inosed with melanoma of the skin between 2005 and 2009 were under the age of 20. That means that of the 76, 250 estimated new cases of melanoma this year, about 458 of them will fall into this age range.

In 2008, Mary Gill was doing what most 18-year-olds do their senior year: preparing for prom, graduation from Reading High School, and a new chapter of life in college. But what should have been a spring season of worry-free, presummer celebration changed into something else entirely one day in May. A month earlier, Mary had found a tick on her back and thought she'd found another. But on closer inspection, she realized that

"Be conscious about putting on sunscreen rather than just thinking you'll be fine today. Because tomorrow. you might not be."

> MARY GILL Melanoma Survivor

the dark spot that had appeared just left of her spine was no tick—it was a mole.

"It didn't look right," she says. "I had a weird feeling. Before, it was a normal freckle and then a month later it was black. It changed color and shape."

Her freshman year, Mary had taken the



From left, Adrianna Manzi and Mary Gill meet during an MEF event. Both ladies were diagonised and successfully fought melanoma while they were teenagers.

Skin Check curriculum as part of her health class with teacher Nels Nelson. In the course, students are given a brochure with photos that demonstrate the ABCD properties of radial melanoma—asymmetry, border, color, and diameter—which Mary kept and affixed to the refrigerator. Two years later, the chart came in handy, and Mary asked her mother, Kathy, to make an appointment with a dermatologist. Eventually, she booked an appointment for August.

Mary's Irish roots are obvious: she has

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SURVIVORS

(FROM PAGE 1)

blonde hair, blue eyes, and clear, freckle-free skin. According to Kathy, they have no family history of melanoma and have never spent an excessive amount of time at the beach. Mary did start tanning as a junior, though, before dances or vacations. She would go two or three times a week a few times a year. Based on these seemingly minimal risk factors, dermatologist Dr. Benjamin Solke didn't think her mole was a serious concern. But Mary insisted it had changed, leading Dr. Solke to move forward with a biopsy.

Four days later, at 8:45 a.m. on a Friday morning, Dr. Solke called the Gill house to speak with Mary. He wanted her in his office that afternoon for surgery.

"That's when we knew it was serious," says Kathy. "She handed the phone to me and started crying and said, 'Talk to my mom, I don't want to hear it." Mary had malignant melanoma. "I didn't think I could get it," says Mary. "All my friends went tanning, so I thought I'd never get it."

Even though Mary had learned about melanoma in school, there was still an air of mystery about the condition.

"We didn't really know anybody that had it," explains Kathy. "We'd heard it was much worse than any other skin cancer. It just sounds like it's bad. It's awful to hear your daughter has it."

Mary was understandably scared. "I just didn't think it was survivable," she says. "I'd only heard of people dying from it, so I didn't think that anything could change [for me]."

But she went in for the same-day surgery, and the melanoma was successfully removed—much to everyone's relief.

"It's the most common cancer, and it's the most curable cancer if it's caught early enough," says Nelson.

Now, at 22, Mary is studying business and accounting at North Shore Community College in Danvers. She wears sunscreen every day, and has traded in tanning booths for self-tanning towelettes. While her friends haven't stopped tanning completely, she does her best to encourage them to be safe.

"I think people should just be smart about [getting UV rays]," she says. "Don't do it every day—when you're out, be conscious about putting on sunscreen rather than just thinking you'll be fine today. Because tomorrow, you might not be."

Mary has regular checkups every 6 months, while Kathy inquires regularly about any new changes in her skin.

While melanoma can affect even those with minimal risk factors, it goes without saying that the opposite is also true. Take 16-year-old Adrianna Manzi for example. Her mother, dermatology nurse Teresa Doherty, has had several dysplastic, or atypical, moles while both Teresa's father and aunt have had melanoma, squamous, and basal cell cancers. Understandably, Teresa has always been a self-described "nut of a mother" who made sure that both Adrianna and her fraternal twin sister, Nicolette, were well protected from the sun.

Two years ago, Adrianna was in 8th grade at Kennedy Middle School in Woburn. In January, she took the Skin Check curriculum with health teacher Anne Ricardelli. In April, Adrianna noticed something strange. "I found a mole on my wrist," she says. "It had always been there but it looked darker than usual. It looked like it had changed colors and I thought that was weird."

Teresa, who works at Harvard Vanguard Medical Associates in Somerville, made an appointment for her daughter with Dr. Sarita Nori right away. Dr. Nori thought that the mole on Adrianna's wrist was a Spitz nevus and that it was concerning, but not melanoma. When the biopsy results were ready, Teresa wasn't in the office, so she called and asked a co-worker to look at Adrianna's chart and tell her what the official diagnosis was.



Above, Mary Gill (second from left) is seated with her mother Mary, boyfriend Dave Bagarella, and father Ed. Below, Mary is with former health teacher Nels Nelson. During her freshman year in high school, Gill learned about melanoma from Nelson, who used the MEF SkinCheck curriculum.

"They kept me on hold and I knew something wasn't right. When they came back on the phone, I said, 'Just tell me what it is, I can handle it,' and they said malignant melanoma. I called Sarita at home and said, 'Tell me, even though I'm a nurse, tell me she's going to be okay.' She told me it was in situ, she's going to be



fine—97 percent of in situ is curable. But I was like really, this is happening?"

Initially, Teresa didn't tell Adrianna it was melanoma because she didn't want her daughter to panic—she explained that it was a bad mole that needed to be removed. Afterward, though, when her stitches were being removed, the PA asked if she understood everything about her melanoma. "I went along with it until she left the room," says Adrianna. "A few days after I found out I was crying and scared." But the mole was removed and all is well—and Teresa, for one, is grateful for the impact the Skin Check curriculum has had on her family. "I don't know if I would have noticed until it was too late," she says. "I try not to go there in my head but that reality could have been ours—we could have had one less daughter." Anne Ricardelli, the health teacher, is also grateful. "I was so happy that she caught the melanoma early. It made me realize that some of the kids were listening—it was a great feeling that the curriculum did have meaning and clearly made an impact," she says.

But Adrianna is the picture of health—her long, dark, curly hair and clear skin glow, her brown eyes hint at the insight one gains from an emotionally trying experience at such a young age. The 16-year-old will be a junior at Woburn High this fall, and also has regular 6 month checkups. Like Mary, she wears sunscreen all the time, and is diligent about staying under an umbrella or wearing SPF clothing at the beach. "I know it could still happen to me in the future so it makes me want to protect myself even more from the sun," she says.

Teresa also suggests that everyone, regardless of family history, should visit a dermatologist at least once a year.

"If nothing is found, then go every 18 months," she says. "Everyone should wear sunscreen every day. I tell my patients to find a moisturizer with SPF 30 because even if you're in the car or it's cloudy, you're getting rays."

Even though it's relatively rare for women so young to be stricken with melanoma, the simple lessons to be learned are true for those of all ages. Educate yourself and those around you about the warning signs of skin cancer, and then check early and often. Go to the dermatologist. Share what you know with others. Wear sunscreen or SPF clothing. Who knows—you may just save a life.

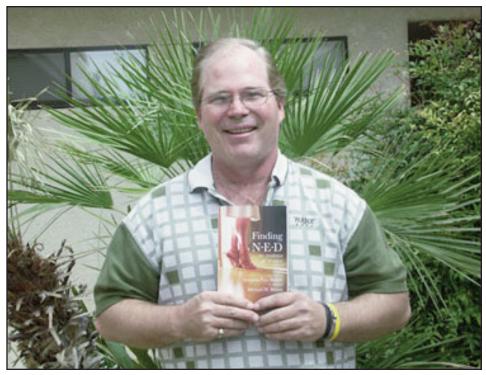
Book Conveys Horror of Melanoma

■ New non-fiction book is author's account on loss of wife to cancer.

ichael Brown, executive director of the Nevada Chapter of MEF and lead saxophonist of the rock band Sha Na Na, tragically lost his wife, Amanda, to melanoma at age 31 in 2006 and wrote a book that chronicles their heart breaking struggle on a very personal level.

The book conveys the real tragedy of this terrible disease and why Michael and all of us at MEF are so intent on preventing others from experiencing Amanda's tragic outcome and Michael's devastation at losing the love of his life. Melanoma has been called "the disease that gives cancer a bad name." Michael's and Amanda's heart-wrenching first-person accounts convey the unfathomable tragedy of the devastating disease better than any other book on the subject.

Finding NED: No Evidence of Disease is a heartfelt true story of love, loss, and hope. Diagnosed with malignant melanoma, Amanda Faye Brown started on a long, difficult journey through the disease, and had the wisdom and foresight to gather her thoughts into a journal. Compiling these journal entries and interspersing them with his own thoughts, telling their story from first meeting through marriage to tearful days at the hospital, Michael Brown shares the struggles and sorrows that came with his wife's cancer. A glossy photograph section in the book shows the stages of Amanda's life; it



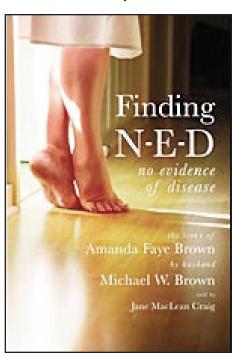
Above, Michael Brown holds up a copy of his new book, "Finding NED: No Evidence of Disease." Below, Brown is shown with his late wife, Amanda Faye Brown.

is devastating to see such a beautiful young woman come to such a tragic end.

Amanda's and Michael's beautiful, poignant story is a treasure.

No wellness teacher who reads this book could even think of not presenting a melanoma lesson to students. And anyone who reads about the horrors of the disease would have to be suicidal or brain-dead if they didn't start checking their skin regularly for early warning signs. Nearly every





melanoma death could have been prevented by early self-detection but, as this book so chillingly portrays, it is often a horrific, extremely malignant, incurable cancer when found at a late stage.

The book may be ordered online as a hard copy or eBook from the publisher or from third party resellers such as Amazon.

First "Check for Change" Triathlon a Success

The first annual MEF "Check for Change" Triathlon was held on Sunday, August 26 at Chicopee State Park in Massachusetts. The USAT-sanctioned triathlon was organized and directed by Steve Facchetti, MEF's newest board member, with the help of a dedicated committee of volunteers. Planning for the event began in the Fall of 2011 and included getting permits, enlisting sponsors, EMS support, lifeguards, event volunteers, and police support as well as publicizing the triathlon to attract participants.



From left, Jill Roethke, Steve Roethke and Karin Roethke-Kahn stop to pose for a picture before the event.

Calendar of Events

October 28

Quarterly MEF Board Meeting. 1 p.m.

November 4

New York City Marathon, 5 MEF runners competing

April 26, 2013

Comedy Night Dinner Show, Montvale Plaza, Stoneham, 7 p.m.

May 1 thru June 30, 2013 Annual MEF Calendar Raffle

August 25, 2013

2nd Annual Check for Change Triathlon, Chicopee State Park



Above, the first annual "Check for Change" Triathlon winner Paul McCloskey is shown approaching finish line. Below, athletes starting the swimming leg of the triathlon. Bottom, athletes check out the results board to find out how they did after the race. The Second Annual "Check for Change" Triathlon is scheduled for Sunday, August 25, 2013.

Over 125 athletes participated, raising nearly \$15,000 for MEF. In addition to Massachusetts the event drew athletes from Connecticut, Rhode Island, New Hampshire, New York, and Quebec.

The triathlon began with a half-mile swim, continued with a 15 mile bike ride through Chicopee, Granby, and Ludlow, and concluded with a 3.5 mile run in the park. Weather conditions were nearly perfect, with low humidity and temperatures in the mid to upper seventies.

The overall winner was Paul McCloskey of Chicopee, with a time of 1 hour 7 minutes and 27 seconds. Bill Reeves from Durham, NH was second with a time of 1 hour nine minutes and 40 seconds.

Although fund-raising by participants was not required, Jill Roethke and her husband and melanoma survivor, Steven, from Nantucket and Steve's sister, Karin Roethke-Kahn, from Milton, enlisted the support of family members and friends to raise over \$4100. Jill completed the triathlon in 1 hour 38 minutes 30 seconds, finishing first in her women's age group.

The second annual Check for Change Triathlon is scheduled for Sunday, August 25, 2013.





TEACHER RESOURCE

Melanoma Lesson Now Online

elanomaeducation.net, a new website for middle and high school health & wellness educators, is now online and ready for streaming of student videos and a new 30-minute teacher-education video.

The free online resources for presenting a short melanoma lesson to students are available to all high school and middle school wellness educators worldwide.

The student lessons are unchanged except in the way they are accessed.

By the end of the 2011/2012 school year the lesson was being taught at 1150 schools in all 50 states.

Detailed information on how to access the online resources is available at www.melanomaeducation.net.

A summary follows:

Getting Started

- 1. Go to www.melanomaeducation.net
- 2. Scroll half-way down the page and click on "Login" if you were the primary contact person for your school in 2011/12. Otherwise click on "Register."
- 3. Complete and submit the one-time online registration form. If this is your first time registering allow up to 3 business days for your information to be entered into our database and to receive a confirmation email message.
- 4. If you have not watched the melanoma teacher-education video or attended a live session previously login and watch the new (2012) 30-minute teacher education video. Watching the teacher-video is a prerequisite for accessing the student lesson.

Lesson Plan

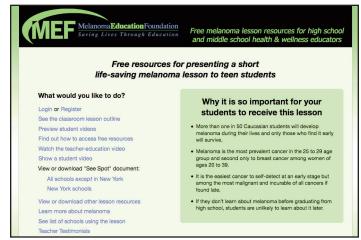
- 5. Download the "See Spot" document at melanomaeducation.net/seespot.pdf. The online document replaces the "See Spot" bookmark but is otherwise similar.
- 6. Click "Login" at melanomaeducation.net to access the middle school or high school student video.
- 7. Adjust the volume to high and the video to full screen for viewing with a digital projector or SmartBoard.
 - 8. Start the lesson by asking the class: How many have ever had a bad sunburn?

How many use tanning beds?

How many have family members who had skin cancer?

- 9. Show the student video.
- 10. Ask the class what they think about skin cancer after watching the video.
- 11. Show students the "See Spot" document, go over it briefly with them, and direct them to copy the web address so they can view it at home.
- 12. Assign students to teach their parents about melanoma at home using the "See Spot" document.
- 13. The second page of the "See Spot" document is a parental verification form.

Direct students to print the form at home, have a parent sign it, and return it to you at the beginning of your next class with them.



A picture of the website: melanomaeducation.net

Questions and Answers

(Complete list is at melanomaeducation.net)

Q: Is the online program completely free? **A:** YES!!!!

- **Q:** Are there any limitations on which high schools and middle schools are eligible for the online program?
- **A:** NO! All high schools and middle schools worldwide are eligible.
- **Q:** I previously joined the program and have the student dvd video and enough See Spot bookmarks for the 2012/13 school year. Is it necessary for me to register?
- A: The short answer is "No" but registering is required to watch the new teacher-education video and to access online lesson resources. We urge all teachers to register even if they have enough resources for the current school year.
- **Q:** I would like to continue using the student DVD video but I'm out of bookmarks. How should I proceed?
- **A:** Download the online "See Spot" document and follow the lesson plan above using your DVD student video instead of the online video.
- **Q:** I would like to take advantage of the online lesson resources but I watched an earlier version of the teacher-education video. Is it necessary to watch the new teacher-video?
- **A:** No, but if it has been more than 4 years since you watched the teacher video or attended a live presentation we urge you to watch the new video to learn important new information.
- Q: Can students access the student videos directly online?
- **A:** No. For more information see questions and answers at melanomaeducation.net.

BEHIND THE SCENES

Transition to Web Delivery of Melanoma Lesson

Thill now, the availability of the MEF student and teacher resources had been limited to U.S. high schools and to middle schools in New England, Nevada, and western New York. We wanted to expand the availability of the lesson to all middle and high schools worldwide but it became clear that achieving that goal would require a more efficient means of delivering the lesson than mailing discs and hard copies.

Making the transition from delivery of resources as discs and hard copies to online delivery involved an enormous amount of effort and considerable cost.

The project involved:

- Creating a new web site just for health and wellness educators.
- Major upgrade of our database to allow direct online interaction with teachers.
 - Finding a service to host the database.
- Updating and shortening the melanoma teacher-education video.
- Finding a service to host the teacher and student videos.
- Testing, testing, and more testing to ensure the various components of the new system functioned as intended.
- Debugging to resolve inevitable issues as teachers start using the new system.

Teachers no longer have to rely on other teachers to borrow student videos or to order "See Spot" bookmarks for their students and they can watch the latest teacher-education video anytime they like.

There are no limitations on availability of the lesson resources; any middle or high school health/wellness teacher in any public or private school worldwide may take advantage of the free online program. The resources are also available to curriculum directors at local, district, and state levels so they can determine whether they are comfortable with approving the lesson for their schools.

We are excited about the potential of the online initiative to

Volunteer Opportunities with MEF

as your life been impacted by melanoma? If it has, and you want to save other lives from the tragedy of this disease, we would love to have your help. Whether you have just an hour or two weekly or more time we probably have opportunities for you. Some examples:

*Search the web for school-related information.

Plan and coordinate an entertainment, dinner, athletic, winetasting, raffle, or other fundraising event.

*Sell special event tickets to family, friends, and colleagues. Our events are awesome!

Volunteer at special fundraising events.

*Conduct new outreach projects.

*Help get the MEF melanoma lesson into additional schools.

The activities marked with * can be done online at your own home.

All of these activities will help save more lives. If you are interested just complete an online contact form at http://www.skincheck.org/contact.php

save even more lives.

We also realize that a project of this complexity is likely to have some (hopefully minor) glitches during start-up so I would be grateful if you share your experiences (both good and bad) with the new program and let me know of any bugs you encounter so we can correct them as quickly as possible. You may contact me at steve fine@comcast.net.

■ WEBSITE

(FROM PAGE 5)

Q: Is there a way for schools without digital projectors or SmartBoards to use the student lesson?

A: Yes, U.S. high schools and middle schools without these resources are eligible to receive a free DVD student video. A question on the registration form asks whether your school has classroom projection capability so we will know whether you need a DVD.

Q: There are several health teachers at our school; is it necessary for all of us to register?

A: It is to the advantage of all teachers who would like to use the lesson to register so they can access the online resources without the need of relying on another teacher whenever they want to present the lesson.

O: Can teachers watch the videos at home?

A: Absolutely!!



MISSION STATEMENT

The Melanoma Education Foundation is a non-profit preventive health organization that saves lives by promoting greater awareness of melanoma and the importance of early self-detection. The Foundation evolved from a father's website tribute to his son, Dan Fine of Peabody, who died of melanoma in 1998 at the age of 26, and was incorporated as a non-profit 501(c) (3) organization in Massachusetts in August 2000.

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