

WALK NEWS

ALZHEIMER'S ASSOCIATION - GREATER MICHIGAN CHAPTER | MAY 2014

Son Shares How He Coped With Mom's Alzheimer's Disease

There's no getting around it, no sidestepping the truth. As early as I can remember, my mom used to tell me the truth hurts. And, when we say that Alzheimer's disease is crippling, horrifying and painful, we're being brutally honest with ourselves. I know because I lived and breathed it for more than three years.

My mom, Shirley, was diagnosed with early-stage dementia in 2010. It hit my family like a ton of bricks. When the neurologist shared the excruciating news with my sister and me, just minutes after administering a memory test, a test that I painfully watched her fail miserably, you could have knocked me over with a feather. I remember looking at my sister, a large teardrop resting helplessly on her cheek. And, I remember my right leg beginning to shake. I sought air, any air, to breath.

But here we were, like so many others before and currently with us, ready to embark on a journey that affects more than 5 million Americans every year. Make no mistake. It was painful watching my mom slowly fade before my eyes.

My mom spent 21 months in the memory care unit of the local assisted living facility. She had her good days, she had her bad days and a whole bunch of days in between. During that time, she never lost the ability to smile, the taste for chocolate cake and the ability to squeeze a hand only like a loving mother can.

Alzheimer's is the sixth-leading cause of death in this country. That we know. What we don't often know is what to do, how to cope with a loved one who has this crippling disease. I wish I could wave a magic wand and spread abundant wisdom to anyone who is dealt this hand. I can't. Yet, here's what I learned:

One, *It's ok to be angry, but it's not ok to be angry at your loved one.* I struggled with this for quite some time, particularly in the beginning. I remember getting angry. That bothered me. "Your mom has Alzheimer's Jim," I said as I looked at myself a half dozen times in the mirror. "You cannot get mad at her ... she's trying. It's not her fault." But, you want to blame someone. It's ok to get angry, to become frustrated because you can't fix the problem. (next page)

WALK LEADERS

Top Teams

1. Janice Hurt - \$3,245 (GR)
2. The Longest Goodbye - \$3,027 (Detroit)
3. Real Estate One - \$2,405 (Detroit)
4. Walking for Mary Ann - \$2,112 (Holland)
5. Quicken Loans - \$2,003 (Detroit)

Top Participants

1. Janice Hurt - \$3,060 (GR)
2. Lenore Wengert - \$2,417 (Detroit)
3. Melissa Kooyers - \$2,112 (Holland)
4. Mary Sue Eiter - \$1,518 (Holland)
5. Judy Mirabatur - \$1,120 (Detroit)

Fundraising Tip: Can You Spare Some Change?

We all have it - it weighs down our purses, clutters our cars, or maybe sits in a jar - spare change. Why not put it to good use?

The Alzheimer's Association - St. Louis Chapter encourages walkers to partner with local grocery stores for team collection day(s). Make sure to contact the store manager to secure permission, then schedule a few hours to stand outside of the grocery store with your teammates during a busy shopping time and ask for a donation. Bonus tip: while you are talking to the manager ask if they'd be willing to sell our point of purchase paper Forget-Me-Nots at the cash register for \$1!

Along the same lines the Northern California and Northern Nevada Chapter shared one of team captain Joanne Dowell's idea. Joanne owns a shop and she asks customers who are paying by credit card if they'd like to round up their total with the extra change going into a Walk to End Alzheimer's donation jar on her counter. Almost all customers say yes and sometimes even decide to make a larger donation than simply rounding up. Joanne has already raised \$30 this month with her keep the change fundraiser. Who do you know that can help implement this?





Jim & his mom, Shirley

Son Shares Continued

Two, *It's not ok to stop visiting your loved one when he/she reaches the stage of Alzheimer's when they no longer recognize you.* A 50-something man recently approached me at a book signing and said, "Jim, how did you do it? How did you keep visiting your mom even when she no longer recognized you? My mom reached that stage four months ago and ... I can't go. It's too painful ... I just can't." This was powerful stuff. I looked at him and said this, "I can't deny it's difficult. It's awful. But here is how I approached it, when I went to visit my mom, and when I held her hand, my mom may not have known my name and

she certainly didn't know I was her son. But, she did know there was a loving presence in her life. That is what gave me hope because I didn't want to have any regrets when she breathed her last breath." The man smiled and walked away. Five minutes later, he returned to my table and leaning over to me, whispered, "Jim, thank you. I'm going to see my mom tomorrow morning."

That made my night. Although my mom slowly lost her ability to reason and carry a conversation, she never lost her heart and those beautiful things that made her so special to all those who had the privilege of knowing her. It's an arduous journey and, sadly, my mom's journey ended on April 28, 2013. But during it, I loved and I loved often.

Jim LaJoie is a regular participant in our Marquette Walk to End Alzheimer's and author of *Hi Mom. It's Me* (available for purchase on Amazon). Excerpts were included in this article. A portion from each copy sold is donated to the Alzheimer's Association - Greater Michigan Chapter, UP Office. Do you have a story to share? Contact Hannah (hdayton@alz.org | 616 459 7467).

A Note from our Event Director

This year marks my fifteenth Walk to End Alzheimer's and eighth as a staff member of the Greater Michigan Chapter. But I speak for many of my colleagues when I say I would gladly work myself out of a job.

In keeping with the determination to end Alzheimer's, the Alzheimer's Association has set an ambitious goal to double our fundraising revenue in the next five years to support research and programs. Our Walk Staff Team is wholeheartedly committed to this endeavor, including our newest member, Kelly Bailiff the Walk Manager for the Detroit Walk to End Alzheimer's who joined our team last week! We ask you to help us reach the goal of doubling revenue to better reach our vision of a world without Alzheimer's, by joining us if you haven't already registered for Walk or ramp up your fundraising if you already have. Together we can make a difference!

Shawn

**Our brochures and posters will soon be ready for distribution!
Can you help us get the word out?**

Please contact your local Walk Staff (third page) if you are available to help distribute promotional materials. Your nail salon, hair dresser, dry cleaner, grocery store, place of worship, community board and neighborhood hot spot are great drop off points! The more people we reach, the more people we have involved and the greater impact we make!

UPCOMING EVENTS

TODAY! Wednesday May 21

Call-In Walk Info & Tips Session
Dial in to talk to Event Director Shawn Ruetz about your Participant Center and share fundraising tips with Walkers Chapter-wide Two calls, 12:00 - 1:00 pm and 5:30 - 6:30 pm.

Thursday June 12, 6:30 pm

Montcalm County Kick Off

Green Acres Greenville
1601 Winter Creek Court, Greenville 48838
Featuring speaker Mary Ceccanese
"The Power of Gratitude and Its Impact on Alzheimer's Disease"
Silent Auction at 8:00 pm

Wednesday June 18, 4:30 - 7:00 pm

Grand Rapids Kick Off

Peppinos Downtown
130 Ionia Avenue, Grand Rapids 49503
Stop in to talk to staff and committee members about getting your team started out on the right foot. RSVP to (hdayton@alz.org | 616 459 7467)

Are you having a Walk fundraiser you would like included in our newsletter or on Facebook? Contact Hannah (Info above).



WELCOME NEW GRAND CHAMPIONS CLUB & CHAMPIONS CLUB MEMBERS

GRAND CHAMPIONS

Melissa Kooyers, Holland
Lenore Wengert, Detroit

CHAMPIONS

Kathy Hutchins, Holland
Kris Cleary, Grand Rapids
Mary Ceccanese, Montcalm County
Sarah Smith, Grand Rapids
Shawn Campbell, Grand Rapids

Join them! Raise \$500 to join our Champions Club and \$1,000 to join our elite Grand Champions Club!

Raising the Priority Level: Alzheimer's Advocacy Efforts

Alzheimer's disease is devastating. It affects over 5 million families nationwide, including over 170,000 in Michigan. It is one of the most critical public health issues facing America. If nothing is done, the prevalence of Alzheimer's disease is expected to skyrocket in the coming years as our population ages.

Alzheimer's is very costly – both to families caring for someone with the disease and to our nation--one in five Medicare dollars is spent caring for someone with Alzheimer's. We must take action now to change the current trajectory.

“Three years ago my life took a very unexpected change in course. In 2011 at the age of 56, I was diagnosed with younger-onset dementia probable frontotemporal dementia (FTD),” **Terry, a member of our national Alzheimer's Association Early-Stage Advisory Group, wrote.** “But my journey, although altered, is by no means over. I have chosen not to let this disease isolate or silence me...As an advocate, I have chosen to use my voice while I still can. It gives me a sense of

purpose, and a reason not to give up. I encourage others living with Alzheimer's and related dementias to consider advocacy as a way to feel empowered and engaged in their own lives.”

Whether you are living with dementia, a caregiver or a champion of the cause you can help change the future of Alzheimer's by participating in the Association's unrelenting advocacy for public policy issues and critical research funding. To achieve our vision of a world without Alzheimer's, we need you to become a volunteer advocate today by visiting www.alz.org/advocacy. You'll receive timely alerts with simple actions that will help influence national policy and spread awareness of Alzheimer's.

To learn more about the Alzheimer's Association - Greater Michigan Chapter's advocacy efforts, contact our Director of Public Policy, Lindsay Bacon (lbacon@alz.org | 248 996 1059).

We want to hear from you!

If you have any questions about Walk don't hesitate to contact your Walk staff:

Hannah Dayton (hdayton@alz.org | 616 459 7467)
Shawn Ruetz (sruetz@alz.org | 616 301 3230)

You can ask Event Director Shawn Ruetz about any of our Greater Michigan Chapter Walk to End Alzheimer's events.



THE GREATER MICHIGAN CHAPTER HAS RAISED \$136,376.16 OF OUR \$1,088,000 GOAL!



WELCOME TO NEW CHAMPIONS CLUB & GRAND CHAMPIONS CLUB MEMBERS!

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