



# Run with it!

Newsletter of A2A3 • Spring 2011

## A2A3 Events at a Glance

**3rd Annual Box Car Derby**  
**Sat., March 26**

**April Fool's Twinkie Run**  
**Fri., April 1**

**Matt at Boston Marathon**  
**Mon., April 18**

**A2A3 at Burns Park Run**  
**Sun., May 1**

**A2A3 at Dexter-Ann Arbor Run**  
**Sun., June 5**

## Coming Up! 3rd Annual Box Car Derby & Picnic



If you haven't yet felt the joy of zooming down South University in a box car – or the joy of cheering on those who are – this is the year! Join us on Saturday, March 26 at 10:00 a.m. at Phi Delta Theta Fraternity. To register or for more information, visit [www.a2a3.org](http://www.a2a3.org).

## New FUN Event! (No Foolin'!)



In honor of a friend with a good sense of humor who died of ALS three years ago, a local runner is joining forces with A2A3 to bring you the April Fool's Twinkie Run. In this fun-spirited 5K, you actually get a time reduction if you eat a twinkie! Free twinkies and prizes are part of the fun! The race starts at 6:15 p.m. near the canoe livery at Gallup Park on Friday April 1. Registration: \$15 for adults and \$10 for youth if registered by March 29. See [www.a2a3.org/Twinkie-run](http://www.a2a3.org/Twinkie-run).

## A2A3 Fall Events Wrap-up

**Family Field Day 2010.** We had a beautiful fall afternoon at Burns Park to run relays, chase scavenger hunt items, play an awesome game of kickball, participate in sports clinics and enjoy delicious food. We had a special guest - the new Burns Park PE Teacher, J. R. Leonard. Kids were delighted as he led us all in an active, fun warm-up. And we played a new game, Pétanque, thanks to Howard Ando and Jane Wilkinson. Many thanks to our sponsors, to all who participated and to our wonderful volunteers!



**1st Annual Masters Holiday Swim Relays.** The season's first big snow on Sun., Dec. 12 didn't stop A2A3's 1st Annual Holiday Swim Relays at Skyline High School. Swimmers enjoyed a terrific roster of relays, including the fun "t-shirt" relay, in which each team member swam one lap in a t-shirt and then had to transfer that shirt to the next swimmer! To see this highlight and more, check out the video & photos at [www.a2a3.org](http://www.a2a3.org).



To date, A2A3 has donated  
**\$64,500**  
to ALS research.  
**THANK YOU** for  
your support!

## Personal ALS Stories

Many believe that ALS is a rare disease, but in fact a new person is diagnosed with ALS every 90 minutes. Once you start talking about ALS, you quickly learn how many people have their own personal story about the disease. In this issue, we share the stories of four people right here in Ann Arbor.



**On a crisply beautiful, October Sunday morning last fall**, eight members of our family and countless friends donned bright blue A2A3 shirts and joined the exuberant throng of thousands for the Big House Big Heart Run. It was exhilarating to be there together joining our efforts with so many others helping to raise urgently needed funds for ALS research.

While statistics vary, it's generally accepted that about 10% of the cases of ALS are the familial (inherited) form. Our family knows more about this than most. And so, we also ran that day to honor the memory and valiant bravery of six family members who've been taken from us by ALS. Each new diagnosis was a crushing blow, because while much has been done, the prognosis for ALS remains bleak. In our family the course is swift because the onset takes the bulbar form that affects speech, swallowing and breathing.

There's heartbreak and inspiration, and yes, even humor in each of their stories; tender moments of secrets shared; fun and laughter that made the journey through it easier to bear. Interestingly, studying family "clusters" like ours may speed the research efforts that will lead to better understanding the disease in general, and define more clearly the path toward an ultimate cure. Our family has been blessed to be a small part of that ongoing research. In tragedy there are always triumphs.

Through our family's connection with the Washtenaw County Farm Bureau we partnered with A2A3 to sponsor the Country Meets City Square Dance in May 2009. Our family also enjoys volunteering for and participating in many A2A3 events including Family Field Day and the Box Car Derby. A2A3's creative energy and activities have fostered a wonderful community spirit of healing and support and our family is proud to be a part of that. Their efforts provide our family with a positive outlet for our grief, helping us to move forward in hope and solidarity.



*Front: Ben Stidham. Second row: Elizabeth Stidham, Kaitlyn Meister. Third row: Laura Stidham, Alyssa Meister, Kathy Siler. Back: Mike Stidham, Mark Meister.*



**ALS. There's a lot of sorrow that this disease has brought to our lives.**

My father-in-law, Jim, was diagnosed in May of 2008, and passed away on October 1, 2010. One of the most heart-breaking parts was watching my children lose their grandfather, whom they called "Papa." For the last 13 months of Jim's life, he lived right across the street from our family. Alex (age 8) and Jameson (age 4) saw the changes the disease brought in their grandfather. They saw us helping Jim up after bad falls and feeding him meals; they saw our worry and concern over how to care for Jim as the disease progressed.

But through the grieving and pain, they saw a family pull together to love and support each other through difficult times. They saw joy, strength and resilience. I like to think that their world grew and expanded through this experience.

Sometimes, as boys do, they just had fun. For instance, one night last spring Jim wanted to go with my oldest son, Alex, to a Cub Scout Cake Auction. The plan was for Jim to go on his motorized wheelchair and for Alex to ride with him on his scooter; my husband, Stefan, would meet them at the school.

They were all set to go when Stefan realized that the event was actually at a different elementary school, over a mile and a half away, over some rough sidewalks and down a very steep hill. What to do?

It was a beautiful night, and Jim and Alex were feeling quite ambitious. Determined, they took off together on scooter and wheelchair, despite the distance and the terrain.

I can't help but imagine the thrill and the sense of freedom that they both felt on this adventure. Jim had long lost the ability to drive anywhere by himself, and even with the motorized wheelchair he wasn't embarking far. Alex was allowed to venture within close proximity to our home and our trusted neighbors. But now, the combination of these two adventurous souls made it possible for them to extend their reach. Alex was able to take his scooter much farther than ever before, because an adult was with him. However, if anything happened to Jim, Alex would be responsible for summoning help. It appeared to be the perfect symbiotic relationship for a young boy to expand his horizons and for a man to reclaim some of his autonomy.

I found out about the excursion after it was underway and thought immediately of all scenarios of something going wrong. But they came back safe and sound, and they were glowing. Alex enthusiastically reported, "The cake auction was so much fun! The ride was great! Papa bought me an awesome cake!"

It is memories like these that I hope my sons recall when they think of their Papa. Joy in the midst of struggle; new adventures born out of challenges. ALS did (and does) bring grief to our family; however, through this experience we also learned to embrace happiness and delight in whatever life hands to us.



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## Check out a2a3.org...

...to read more about the first human clinical trial of a stem-cell treatment for ALS being led by Dr. Eva Feldman. Read about ALS TDI, which has been given the highest rating of all ALS organizations by Charity Navigator, with 86% of all funds raised going directly into the lab.

## Thanks to Borders!

December 4th and 5th were A2A3 benefit days at Borders! Here in Ann Arbor, and on-line throughout the country, A2A3 supporters were shopping at Borders. We raised \$1,763. Many thanks to Borders! And many thanks to our shoppers – Borders praised this as one of their best fundraisers!

## Marathon Man

Matt Barnes will be running in the Boston Marathon on April 18 for the second year in a row. He is hoping for new Personal Bests in race time and fundraising! <http://www.a2a3.org/matt-barnes-runs-boston-donation-page/>

## Register Now for the Burns Park Run!

The 33<sup>rd</sup> Annual Burns Park Run 5K, 10K and Fun Run will be held Sun., May 1! Kick off Spring with 1,000+ friends and enjoy Zingerman's bagels, Caribou coffee and homemade goodies during the post-race brunch. Visit [www.burnsparkrun.org](http://www.burnsparkrun.org) for details and registration.

**ANN ARBOR**  
**Active Against ALS**

2020 Shadford Rd.  
Ann Arbor, MI 48104



## Personal ALS Stories (cont'd)



**Stan Bielby, a long-time resident of Ann Arbor, was 44 years old** and a father of three boys when he was diagnosed with ALS. Stan met his wife Nan through mutual friends while Nan was a student at U-M in 1955; they married in 1956.

Stan was an integral part of the Ann Arbor community, working as an Electronic Technician at the University of Michigan's Human Performance Center; coaching his sons' sports teams (especially baseball), serving as the Cub Scout leader of Pack 5 from Eberwhite School, and as president of the PTO Council. Stan was passionate about his work and his family.

Though many descriptions of ALS indicate that the disease "leaves the mind intact, while paralyzing the body," this is not always the case. Unlike most patients, Stan's first symptom was not physical - it was mental: "He did things that were not typical of him", says his wife, Nan Bielby Sudia. For Stan, a creative inventor, and for his family, this early symptom of dementia led to uncertainty around the disease.

When these first symptoms occurred, doctors thought Stan's condition was a psychiatric illness. After consulting a psychiatrist, however, Stan and Nan were told that Stan's decreased mental function was attributable to Organic Brain Syndrome, which means it's due to a medical disease other than a psychiatric illness. They then consulted Dr. Russell N. DeJong, a prominent neurologist at the University of Michigan, for a second opinion. He confirmed the ALS diagnosis and told them "everyone's case is different."

Stan's physical symptoms did eventually progress, but his legs remained strong. He developed a passion for roller skating which probably came from his youth when he was an active ice skater and hockey player. Nan recalled, "Even when he did not have the use of his arms, he still went roller skating a few times a week."



Even though Nan had hoped she could shelter her sons from the effects of this painful disease, family life changed for all of them.

**Stan's story, and in particular his suffering from ALS-related dementia, can help raise awareness that indeed every case of ALS is different.**

Caring for Stan was something that Nan, Michael, Gordon and Peter did together, and helped them to maintain their connection as a family in the face of a devastating disease. Stan passed away on July 29, 1981, at the age of 46.

Nan emphasized that "what A2A3 is doing is very important work." Research funds are urgently needed, but in addition, A2A3's emphasis on raising awareness about ALS is critical. It makes a significant difference in the lives of those who have ALS when the disease and its effects are understood. Stan's story, and in particular his suffering from ALS-related dementia, can help raise awareness that indeed every case of ALS is different.



Jennifer Ross, who works at Morgan & York -- one of the local companies that has supported A2A3 since our kick-off event in 2008 -- never spoke much about her mom's diagnosis and ongoing battle with ALS. This past December, however, she noticed A2A3 volunteers working the gift wrapping table and stopped to learn more about A2A3; she shared that her mom, Doris Ross, has had ALS for six years.

Jennifer, an architectural historian who recently moved to Ann Arbor from Florida, explained that she doesn't discuss her mother's story because she feels that the general public has a lack of understanding about the disease and its impacts. She was interested to learn about A2A3's efforts and was also happy to talk with A2A3 president Suzanne Ross about her mom.

In describing her mom, Jennifer smiles and says, "She is fiercely independent and she sees ALS as just another thing to deal with." Doris was born in Beaumont, Texas in 1940 as one of ten children. While her siblings stayed in the Houston area, Doris ventured off, relocating first to San Francisco and then to Chicago where she met her husband and they together raised seven children. While there, she was a general contractor, enjoying "working with the guys and being very hands on." She was always passionate about being active, owning her own health club at one point.

In March 2005, Doris was diagnosed with ALS after noticing weakness in her legs. The doctors gave her five to nineteen months to live and recommended a tracheotomy and a feeding tube. A devout Christian, Doris believes that doctors are not the ones who determine when people die, and she thus said no to the procedures. To make this ALS diagnosis even more devastating, Doris's husband was diagnosed with Parkinson's at the same time and died a year later. Doris relied both on her religious faith and her family for strength during these very challenging moments.

Currently, Doris lives with one of her daughters, Damara, in Arlington, Va. She continues to do most everything for herself, even though certain things take awhile. In August 2010, she progressed to needing an electric wheelchair, but she sees this as a positive step because it has actually increased her independence and taken away the worry about falling. Rather than focus on what she cannot do, Doris emphasizes the many ways she can take care of herself – fixing her own breakfast, dressing herself and getting herself via cab to the doctor's office. She has traveled to Hawaii four different times since 2007 to visit grandchildren and to Australia in 2010 to visit her daughter, Michelle. She enjoys keeping up with her seven children and five grandchildren via email and Facebook. And she has been writing an almost-finished book, *Diagnosed with ALS March 2005: I Don't Have Time To Die*.

Because Doris loves "living the single girl life" when she can, her kids have made plans to take turns staying with her in her condo in Chicago this summer so she can enjoy the city that she loves, during her favorite season.

After learning about A2A3's efforts in this community, Jennifer believes it will be easier to share her own family's story to help others understand this complicated disease.



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