

Mark Your Calendar

Support Meetings:

When:

May and June, first
Saturday of the month

Time:

Business Meeting:
6 – 7 p.m.
Support Meeting:
7 – 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg
Private Dining Room

Special Events:

Jul 23-27:

11th International
Fragile X Conference,
St. Louis, Missouri

Aug 10:

Annual picnic and
Fragile X 5K Fun Run
& Walk
Independence Oaks
Clarkston, MI

Fragile X Association of Michigan

Contact Information:

313-381-2834

fraxmich
@hotlinemail.com

Fragilex.org/html/
michigan.htm

Earning our wings

By Sally Nantais

During March, Austin and I completed our fifth and final visit for our four-year study, to the Waisman Center in Madison, Wisconsin, for the FXS Language and Communication Study.

He did absolutely awesome!

Ten years ago, I would have never dreamed that Austin would be such an accomplished traveler.

How did we get here? The key to our success was first in understanding Austin, looking at the journey from Austin's perspective, understanding his anxiety and fears and taking measures to ensure they were minimized.

Five years ago, before our first trip, we began with a family field trip to Detroit Metro Airport in which I was able to expose him to many aspects of air travel. It was an opportunity to take away many of the unknowns. It was an experience that not only benefited Austin but his sisters, Natalie and Genevieve, as well.

Every trip was carefully planned taking into consideration what I could do to make the trip successful. We always travel non-stop, reducing transitions and wait times, and the potential for unexpected delays. At first, we only traveled during Austin's best time of the day, the earlier the better. As time passed, we became more adventurous for our return trips home, traveling late in the evening.

We had our unexpected

adventures, spending two hours on Detroit's runway on one trip waiting to be deiced (that was the last time we scheduled a trip in February.) Once we even made a mad dash to the airport in Madison to try to get home earlier by going standby on an afternoon flight. As luck would have it that would be the one trip we were randomly selected for intensive security screening but we managed very well with no meltdowns due to strange people unpacking his treasures in his backpack.

With every trip, Austin's Teddy has accompanied us. Austin doesn't sleep with Teddy anymore but he always digs him out of his toy box and brings him along for our journeys. Teddy is part of our routine and routines are very important to Austin.

Austin has navigated shuttle buses, taxis, escalators, moving walkways, elevators and express trains like a pro. We always pre-board the plane, eliminating waits and being crowded by others. His only issues have been with the connecting walkways from the terminal to the plane. This phobia (or whatever it is) occurred after our Disney World trip in 2005. It's classic OCD behavior, reminding me of Jack Nicholson's character in "As Good As It Gets". When Austin approaches a seam in the walkway, each seam, I had to coax him across, reminding him, "It's okay, the floor won't move."

During our last trip home, he



got to the final platform where he would enter the plane and he froze. I had already entered the plane, I waited for him, telling him "It's okay, follow mom." You could see the fear on his face. Then something unexpected happened, the flight attendant (who happened to be male) went around me, went to Austin and said "c'mon buddy, it's okay, we can do this" and he did.

Austin has earned more than just his wings on our adventures; he's entered my world and mastered it better than a few adults I know. He's not the only one who has earned his wings. Numerous people along the way, like the flight attendant who helped him board the plane or the staff at the Waisman Center who always make sure our needs are met; they have earned their wings, on a very different level.

Fragile X Advocacy

To think that back in 2004 I almost didn't participate in Fragile X Advocacy Day. I was unfamiliar with politics, a little intimidated with the process and not feeling as if I had power to make changes in Washington, DC. Four years later, with five visits to Washington "under my belt", I know how wrong I was back then and how much I would have missed out on had I not begun to get involved in the advocacy process.

In 2004, the National Fragile X Foundation made remarkable strides advocating for fragile X and achieving their goals in the first go-around. Their goals were accomplished by the many families and friends who met with their elected officials and simply told their stories of how their lives are affected by fragile X.

Every year that I go to Washington, I tell my story. The story of my family and how fragile X has impacted our lives. I also always bring all of you with me when I go. I remind those in Washington of the many

By Kim Young

wonderful families in Michigan who could not be there with me, but who have much to say about their lives and fragile X.

This year, we again asked for an additional \$1 million in funding through the Centers for Disease Control (CDC), that appropriations report language be supported by the National Institutes of Health (NIH) and for \$5 million in new funds for Special Programs of Regional and National Significance (SPRANS) grants initiative within the Health Resources and Services Administration (HRSA) to strengthen states' newborn screening programs. But this year brought new excitement with the addition of legislation being introduced on behalf of individuals with disabilities and the laws surrounding saving for the future. The Financial Security Accounts for Individuals with Disabilities (FSAID) Act, if passed, will allow individuals with disabilities or their families to create a disability savings account that would accrue tax-free interest.



I am fortunate to be able to take part in Fragile X Advocacy Day each year. It is an empowering experience and I am proud to be a participant in it. Consider joining me next year. The only thing you have to be an expert in is fragile X and your family. No one knows that story better than you!

For more information on year-round advocacy efforts by NFXF and ways in which you can participate, visit fragilex.org and click on public policy/legislative advocacy

Do you have a graduate you'd like us to spotlight in July?

(kindergarten, elementary school, high school...)

Contact Mary Beth at mblangan@hotmail.com or 313-881-3340

They always say time changes things, but you actually have to change them yourself.

Andy Warhol

Scholarship Opportunity for 2008 International Fragile X Conference

The FXAM Board met earlier this year and passed a motion to once again approve a \$5,000 scholarship fund for the 2008 Fragile X Conference, in St. Louis, Missouri from July 23-27. This scholarship is available to all current FXAM members and family members.

All requests must be in writing and emailed or mailed and postmarked by **April 25**. Requests should include the names of all adults from the family wishing to attend the conference, as well as the necessary contact information (including email address and/or telephone). The scholarships are not awarded based upon income. The funds will be dispersed evenly to all applying

adults.

Scholarship recipients will be notified of the awarded amount by May 10. After the conference, recipients must submit receipts to the FXAM treasurer, totaling or exceeding the awarded amount. Checks will be distributed after receipts are received.

The deadline is upon us!

You will not receive another reminder of this benefit. Please remember to send in your requests on time in order to assure yourself assistance in attending the 11th International Fragile X Conference.

Mail or email scholarship requests to:

FXAM

c/o Kim Young
2919 St. Jude Drive
Waterford, MI 48329

OR

young4mi@comcast.net

Early registration deadline for the conference is **May 15, 2008**. For additional conference information, visit fragilex.org. Hope to see you in St. Louis!

Questions?

Contact Kim Young

young4mi@comcast.net

248-396-0315

From the President's Desk by Lauren Majeske

Hooray for the hard work of our Michigan families! Our Playing Card fundraiser is off to a very successful start. Sponsorships for the cards sold out in just one week, with cards being purchased by families, Parent Resource Groups across the U.S. and professional organizations such as Emory University, St. George's University of London, Developmental FX, National Fragile X Foundation (NFXF), and many more. Michigan families supported more than 10 of the cards themselves.

Having already seen the proof sheets, I can't wait for all of you to see the end product and be a part of this exciting project. Graphic artist Kathy Nagler designed and donated a memorable design for the back of the card with our theme "Dealing with Fragile X" and the photos submitted by families and professionals will make you smile and be proud to be a part of the FX community.

These cards are an affordable way to spread awareness, while both putting a face to Fragile X and offering pertinent information, with each card holding a fact about fragile X or information on a clinic or other FX related organization. They will make great gifts for both those who know a lot about Fragile X and those who are getting their first introduction. What a fun and unique way to educate your teachers, medical professionals, family members or friends.

The cards are currently being printed and will be available for the NFXF International Conference in St. Louis for \$10.00 a deck. After that we will have them available at our local events and on the NFXF website.



Thank you so much to the team of people who worked so hard on this project. Also, a big thank you to all that supported this effort: our local families, regional families, resource groups,

researchers, doctors, professionals and even the office staff of NFXF who all chipped in to buy their own card. The enthusiasm of FXAM was infectious!



This summer we have a lot of other events to look forward to such as the Family Picnic and Fun Run & Walk, the NFXF International Conference and our annual golf outing.

Come on out and enjoy networking with other Michigan families!

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Fragilex.org/html/michigan.htm



Hosted by the Fragile X Resource Center of Missouri

Online registration for the 11th International Fragile X Conference is now available! Early registration deadline is May 15. **See page 3** for time-sensitive Scholarship Opportunity information!

The conference will be held at the Hyatt Regency St. Louis at Union Station.

Full details are available online at fragileX.org or by calling the National Fragile X Foundation at:

800-688-8765



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