

Three Cheers for Kindergarten Graduates



Kyle Laske

Mark Twain Elementary,
Royal Oak

Favorite subject: Music Class

Future plans:

Carpenter...he'd rather
hammer a baseball into the
tee stand than hit it out to the
field.



Cameron Campbell

North Sashabaw
Elementary School,
Clarkston

Favorite subject:

Reading & Writing

Future plans:

Puppeteer



Three Cheers for Andrew

Andrew Young received the Cub Scout of the Year Award for all of Pack 105, in Waterford, Michigan. The award recognizes honesty, kindness, attendance and completion of achievements. He is going into his fourth year as a scout as a Webelo II.

Our Experience with a Fragile X Clinic

By Kristine Atwood
of the Fragile X Alliance of Ohio



Shannon and Hadden Atwood

We met Dr. Carol Delahunty during early planning sessions held to establish a Fragile X Clinic at Akron Children's Hospital. At that

time, Shannon and Hadden were being monitored by the pediatric neurologist who had diagnosed them with Fragile X four years before. We were very pleased with the medical monitoring done by our neurologist but other issues were not addressed. Dr. Delahunty sparked our curiosity regarding our children's development and therapy. How were our children developing? We hadn't compared our children with others of the same age. Were we focusing on the right therapies?

We first took our son, Hadden, to see Dr. Delahunty. We had just finished his Multi Factor Evaluation (MFE) for kindergarten. We initially thought we had a good plan for his transition. Dr. Delahunty read the school's report and answered our list of questions addressing the usual medical issues of orthotics and medications.

We had been tolerating Hadden's sporadic sleeping patterns. He had trouble sleeping through the night. We would get up and put him back to bed every 4 hours or so. We also accepted other behavioral issues such as food aversions, weight loss, and meltdowns.

Dr. Delahunty not only asked questions; she gave us solutions. Some of her suggestions included adjusting Hadden's sleeping times, scheduling frequent toilet training opportunities and rewards and prescribing Pediasure as a food supplement. We left her office with a list of projects to start.

The Fragile X Clinic's program coordinator scheduled evaluations that were lacking in Hadden's MFE. He needed current speech, hearing and occupational therapy evaluations. The reports were comprehensive (three pages compared to the school's paragraph). The evaluations included short-term and long-term goals which we later incorporated into Hadden's IEP at school.

Dr. Delahunty also mailed a report of her exam to us. The report included recommending a classroom assistant for Hadden. It stated why he needed an assistant and emphasized his difficulty with transitions. We gave his school copies of all reports and the school district provided a one-on-one assistant. With the help of the team at Akron's Fragile X Clinic, our family was better prepared for the challenges of starting school than if we relied on the school's recommendations of what our son needed. The team knows what he is capable of doing and can help us nurture his development.

Our children return to the Fragile X Clinic every three to six months depending on their progress. We are very grateful for Dr Delahunty's help in caring for our children. Hadden became seriously ill earlier this year – not due to Fragile X – and Dr. Delahunty went above and beyond to follow Hadden's treatment provided by his doctors.

Are you interested in the Fragile X Clinic at Akron Children's Hospital? Cindy King is the coordinator and a great help. She can be reached at 330-543-6015 or 800-262-0333 ext. 38050. More info on the Fragile X clinic can be found at www.akronchildrens.org and

www.akronchildrens.org/press/programs/2005/fragilex.html.

My husband, Robert, and I relocated to the Akron area from Michigan in 1995 and we are fortunate to live near Akron Children's Hospital. We travel to Michigan often with the help of DVDs and McDonald happy meals. If you are ever have questions or will be in our area, please feel free to contact us at 330-794-2906 or atwood326@aol.com.

FXAM has brochures available on the Fragile X Clinic in Akron. If you are interested and would like a brochure, contact Mary Beth (contact info is on the last page.) ✕✕

Other Clinics

Here are some of the other options of Fragile X clinics where some of our members have taken their children. The FXAM member listed after each clinic is willing to answer your questions if you would like to contact them about their experience with these clinics.

Clinic: M.I.N.D. Institute at U.C. Davis

Location: Sacramento, California

Staff:

Drs. Randi and Paul Hagerman

Louise Gane

FX or FXTAS: FX and FXTAS

Research: Research opportunities available.

Telephone: 888-883-0961

Website:

www.ucdmc.ucdavis.edu/mindinstitute

FXAM members:

Elina & Tony Gelfand

home 248-661-6758

elina.gelfand@compuware.com

Member quote:

“My whole family, including my parents, visited the M.I.N.D. Institute and went through medical and cognitive testing. What we learned there about FX and FXTAS cannot be substituted by any book or internet research. The best part is that even though Randi, Paul and Louise are thousands of miles away, they are only a phone call away. Whether it is an IEP question, medication or behavioral problem - our questions are always answered right away.” ✕✕

**Clinic: Rush University Medical Center
Fragile X Clinic**

Location: Chicago, Illinois

Staff: Dr. Elizabeth Berry-Kravis

FX or FXTAS: FX and FXTAS

Research: Research opportunities available.

Telephone: 312-942-4036

Website:

www.rush.edu/rumc/page-R12247.html

FXAM member:

Mary Beth Langan

313-881-3340 or mblangan@hotmail.com

Member quote:

“Both my 5-year-old son with FX and my dad with FXTAS see professionals at Rush. It is so wonderful that a top expert in the Fragile X world is only a 5-hour drive away. Dr. Berry-Kravis has been amazingly helpful in between visits.” ✕✕

NEW

**Clinic: Riley Child and Adolescent Psychiatry
Fragile X Syndrome Treatment Center**

Location: Indianapolis, Indiana

Staff: Dr. Craig Erickson

Dr. Christopher McDougle

FX or FXTAS: FX Only

Research: Research opportunities available.

Telephone: 317-274-8162, Option 1

At Indiana University we will use our expertise gained during many years of autism and related pervasive developmental disorders research and clinical treatment to develop a comprehensive clinic for the treatment of individuals with Fragile X syndrome. Starting this month our clinic, located at the Riley Hospital for Children Outpatient Center in Indianapolis, Indiana, opened to new patients with Fragile X. We will provide diagnostic services, ongoing treatment, and research opportunities for children, adolescents, and adults with Fragile X syndrome.

We find the rapid increase in Fragile X associated research exciting and we hope to contribute significantly to this body of work. Currently, we have received a grant from the FRAXA Research Foundation supporting a trial of Abilify (aripiprazole) in individuals ages 6 to 35 years with Fragile X Syndrome targeting aggressive and irritable behavior. We look forward to the opportunity to serve individuals and their families impacted by Fragile X Syndrome across the Midwest.

Individuals and families interested in treatment or research opportunities are encouraged to contact our clinic at 317-274-8162, option 1. ✕✕

**FXAM Directory
Parent-to-Parent Ads**

Does your family operate a business or provide a service that other members might be interested in?

The new member directory will have a section for advertising. Pricing for advertisements is as follows:

1/4 page ad - \$25

1/2 page ad - \$50

full page ad - \$100

Ads will be printed in black & white. If you are interested, please contact Sally Nantais for additional details at 734-282-7910 or sally_nada@iuno.com ✕✕

Hear ye, hear ye...

**5 Things to Consider Doing in Honor of
National Fragile X Awareness Day on
July 22**

- send an email to those on your address list wishing them a Happy Fragile X Awareness Day and sharing with them some information about Fragile X
- create a flyer to share more about Fragile X with your neighbors or religious community members
- make some X cookies in honor of the day to share with folks in your community
- ask your friends and family to skip giving you a birthday gift during this next year and instead make a donation to your favorite FX organization.
- make a goal to distribute 5 Fragile X info cards that day to spread the word



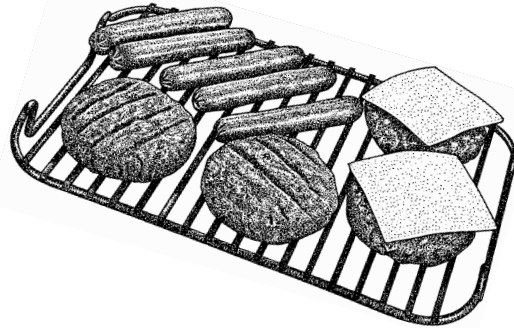
Annual Picnic

When: August 6, 2006
Noon – 4 p.m.
Lunch at 1 p.m.

Where: Boulan Park, Covered Pavilion
Troy, Michigan

West side of Crooks Road between Big Beaver
and Wattles Roads

www.ci.troy.mi.us/ParksRec/parks/Boulan.asp



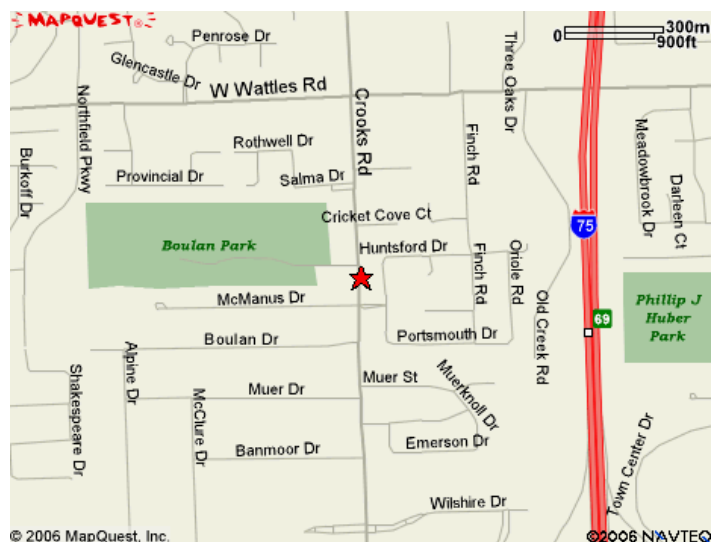
RSVP to Kim at
young4mi@sbcglobal.net
or 248-674-2147
by: August 1, 2006

with # of children and
of adults attending.
Bring your own drinks.

We will provide plates, silverware, napkins, condiments, hotdogs and hamburgers.

Last Names beginning with
A – M, please bring a salad or appetizer to share.

Last Names beginning with
N – Z, please bring a dessert to share.





SIXTH ANNUAL GOLF OUTING

Where: Wesburn Golf and Country Club
5617 S. Huron River Drive
South Rockwood, Michigan
(one mile west of I-75, exit 26)

When: Saturday, September 9, 2006, 12:15 p.m.

For additional information contact Frank or Nina Liberati at 313-381-2834. Registration and sponsorship forms are available on the web at:

www.fragilex.org/html/michigan.htm

From the President's Desk By Lauren Majeske

As this 4th of July passes, I am reminded how thankful I am for the freedoms of our country. I watched my boys sit – and I use the term loosely! – through the fireworks for the first time, after 10 years of attempts. I also enjoyed watching the fireworks through the "eyes" of a blind man and his family – appreciating their descriptions to him and laughing along with him as he jumped from the thunderous sounds, before the sparkles even lit up the sky. The eyes of the younger children glowed in anticipation of the next burst of color and the dancing lights reflected years of wisdom in the eyes of the elderly.

We are fortunate to live in a country where we are able to get together with friends and family. We are fortunate to be allowed to gather as the Fragile X Association of Michigan or to travel to Atlanta to meet with other families and professionals from around the country and around the world at the 10th International Fragile X Conference. We are fortunate to have each other. I am reminded how thankful I am for all of you.

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Through the Maze Featured Website

The Arc Michigan

www.arcmi.org

The Arc Michigan is a non-profit organization that has been in existence for 55 years. The Arc Michigan exists to empower local chapters of The Arc to assure that citizens with developmental disabilities are valued and that they and their families can participate fully in and contribute to the life of their community.

The Arc Michigan contains links to local chapters throughout Michigan and information specific to Michigan when it comes to changes in policy or services available to families in Michigan.

Friday Mail is an electronic newsletter provided by The Arc Michigan. The Friday Mail includes the latest federal, state and local information. Friday Mail is an excellent tool to enable individuals to stay abreast of changes that may affect their loved one with a disability.

Most counties have a local Arc for you to join. When you join at the local level, you automatically become a member of the state and national chapters of The Arc. Membership dues vary in each local chapter. Each local chapter has different opportunities for members. Please contact The Arc Michigan at 1-800-292-7851 or via their website www.arcmi.org to connect with the local Arc chapter closest to you and find out what they have to offer.

Quote for the Quarter

"One of the things that my parents have taught me is never listen to other people's expectations. You should live your own life and live up to your own expectations, and those are the only things I really care about."

Tiger Woods

Mark Your Calendar

Support Meetings:

When: October and November
First Saturday of the month.

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

Where: Beaumont Hospital, Royal Oak
Admin Building, Private Dining Room

Special Events:

**Jul 19-23: International Conference,
Atlanta**

Jul 22: Fragile X Awareness Day

Electronic copies of our newsletter are available on our website. If you would like to share them with family, friends or professionals, please share our web address with them.

Aug 6: Picnic, Boulan Park, Troy
See picnic flyer inside

Sep 9: Annual Golf/Dinner Fundraiser
Wesburn Golf & Country Club
South Rockwood, Michigan

Contact Information:

Phone: 313-381-2834

E-Mail: fraxmich@hotmail.com

Web: www.Fragilex.org/html/michigan.htm

eXtra, eXtra

Editors:

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sally_nada@juno.com

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