

**Mark Your
Calendar**

Support Meetings

First Saturday
of the Month
(No meetings in
December & January)

When:

November 1, 2014
Free Childcare at our
November meeting!
See page 5.

February 7, 2015

Business Meeting

6 - 7 p.m.
(6:30 p.m. in Nov)

Support Meeting

7 - 9 p.m.

Where:

Beaumont Hospital
Royal Oak Campus
Administration Bldg.
Private Dining Room

Special Events:

November 8, 2014

FXAM Moms:
Let's Do Lunch!
See page 3.

December 6, 2014

FXAM Holiday Party
See page 3.

March 3 - 4, 2015

Advocacy Day
Washington, D.C.

**Fragile X Association of
Michigan**

Contact Information:
313-381-2834
FXAM.org

Three Cheers for...

Antonio Liberati Allen Park High School Homecoming King!

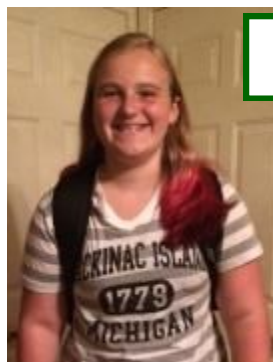
Read more at: <http://downriversundaytimes.com/2014/10/14/growing-acceptance-of-special-needs-classmates-earns-autistic-student-homecoming-crown/>



Nick Hansen

After years of being deathly afraid of needles, 16-year-old Nick, of Newago, MI, was proud that he donated blood this fall!

Back to School



Amber (freshman) and **Adam Popejoy** (senior) are back to school with big smiles!



Fragile X Awareness by

Lauren Majeske, Kailey Owens and Andrew Langan Coutilish

The Knight in Shining Armor

By John and Tina Sobocinski

Starring: Tania Sobocinski and Sir Tyler

To truly appreciate our story, you need to know something of our 22-year-old daughter Tania. All of her life she has been challenged by her cognitive impairment caused by Fragile X Syndrome. However, as a young adolescent, her life became more complicated as she began to exhibit severe social anxiety. Tania's social anxiety is an invisible barrier that prevents her from interacting with the people who love her and want to support her. It is an obstacle that prevents her from enjoying the company and enjoyment of family gatherings. A major goal of Tania's Person Centered Plan is to develop her social skills so she can engage in vocational training. So, for over the past year and a half, she's worked twice a week as a volunteer at the Pontiac Lighthouse filling orders in the food pantry. We haven't noticed any significant improvement in Tania overcoming her social anxiety until this summer when we went to the Michigan Renaissance Festival...

It was on a warm and sunny September Saturday morning when we drove out for an adventure to Holly, Michigan. We were excited with the anticipation of knowing we'd be spending the day at the festival, enjoying comical stage shows, shopping at the artisans' stores, and experiencing the fantasy of a recreated time from the 16th century. Tania has attended this annual event her whole life. She can leave the trappings of her regular life behind and "Live the Legend" of the Renaissance Festival at Holly Grove. Our family has created many wonderful memories at this venue but none as special as what we experienced this year.

We knew it was going to be a great day when we ran into our friend Grey Beard. He normally attends the festival costumed as an authentic Caribbean pirate but surprised us by showing up this year as a Scottish Highlander. Tania always looks for Grey Beard at the festival but she hadn't seen him for

over three years. We crossed his path shortly after we arrived at the festival.

Tania and Grey Beard were equally surprised to see each other again. Grey Beard asked Tania about what she'd been up to lately and remarked at how she'd grown into such a fair young lady. This compliment left Tania beaming with a smile and she was relaxed enough with Grey Beard to allow him to tell her a few jokes. Laughing has a calming effect on Tania, and as she continued to laugh at his jokes, she became comfortable enough to pose for a picture with him. She even told Grey Beard of how she's been volunteering at the food pantry and how she was here to watch the Knights joust. We recognized this extroverted behavior as unusual for her and took it as a good omen as our day at the festival was just starting.

Tania had made the comment to Grey Beard that she wanted to see the Knights' Joust, an event she normally shies away from because of the large crowd and loud cheering. After she confirmed it was something that she genuinely wanted to do, we made our way off the North King's Boulevard, through the Queen's Walk, and over to the Upton Downs Joust Field. We got there just in time to find a row of hay bales with enough space us to sit and have a good view of the field.

As we listened to the Mayor of Holly Grove explain the Joust, we learned the competition would take place between four Knights, each positioned at one corner of the field. The spectators at the adjacent corners would cheer for their respective Knight. At our corner of the field was Sir Tyler, the youngest and most inexperienced of the four. Sir Tyler explained to us that it would help his confidence if we were to cheer for him loudly, so we obliged.

The first event of the Joust was a competition of skill with the lance. Each Knight would ride the length of the field and try to skewer multiple

rings; the Knight with the most rings upon his lance would be declared the winner. It was at this time that Sir Tyler called upon his audience for a "fair young maiden" who he would champion on the field of honor. To our wonder and surprise, Tania volunteered along with two dozen other women, her hand raised up high and waving for attention. After a moment of perusing the audience, Sir Tyler pointed to Tania and signaled that she could come down to him and receive a token of his admiration. When the Mayor came over and asked for the young maiden's name, she excitedly answered "Tania" into the microphone. Our jaws dropped as we watched our daughter step out in front of over 500 people, speak her name into the PA system, and allow herself to be the center of focus, as Sir Tyler gave her a silk rose as a tribute. Once that part of the ceremony was complete, the competition was formally under way. During the joust, we cheered for Sir Tyler like he was truly our daughter's champion. When the joust was over, the Knights dismounted and allowed the audience a chance to pet their horses or ask questions. Tania once again surprised us by going down to the fence rail to speak with Sir Tyler and pose with him for a picture. Even though Sir Tyler didn't win the joust, he still came out a winner with us and with Tania.

It may be the fantasy atmosphere of the festival that allowed Tania to break through the barrier of her social anxiety, but we're still seeing positive effects weeks later. Tania has been demonstrating marked improvement in using her social skills at Lighthouse. She has begun to regularly call out the food orders, call out the recipient's name, and verify with them the order is correct. We're glad to say that Tania's weekend festival fantasy has had a lasting, positive effect on her daily reality.

And the tale continues.

What's going on ...



FXAM Moms: Let's Do Lunch!

Connect with some awesome FXAM moms at lunch!
Our first official event in May was a success so we're planning another.

Saturday, November 8, 2014 at 11:00 am

Blaze Pizza
26401 Novi Rd., Novi, MI 48375
(just South of I-96)
248-773-8955
blazepizza.com

Come join us for some Mom-only time!

Email cabouelseoud@gmail.com and mblangan@hotmail.com so we know to expect you for lunch.
We can then keep you updated if there are any changes in plans.
Last minute texts/questions? Mary Beth's cell: 313-689-3340

Hope to see you on November 8!

Please note: This is not a free FXAM event. Each FXAM mom will be paying for her own food/drinks.

FXAM Holiday Party Our Annual Potluck Gathering

Saturday, December 6, 2014 at 5 pm

Langan-Coutilish Home
Grosse Pointe, MI

More info will arrive via email and FXAM Facebook group or contact Mary Beth at mblangan@hotmail.com or 313-881-3340

If you're not on our email list, please send an email to Mary Beth so you won't miss out on our events!

Fifteenth Annual FXAM Golf Outing

The 15th Annual Fragile X Association of Michigan Golf Outing on September 6 was once again a huge success! The **123** golfers (a record number) teed off at approximately 1 p.m. and everyone had a great time during the 4-person scramble. Afterwards **147** people enjoyed steaks, potatoes, mostaccioli and more under the tent.

The Fragile X Association of Michigan continues to be very grateful to **Nina and Frank Liberati** as organizers of this event each year. The 15th Annual Golf Outing raised approximately **\$18,000** for the Fragile X cause. Way to go Nina and Frank!

We would like to thank all those who came out to golf, sponsored holes, made donations and all those who helped in setting up, working the par -3 closest-to-the-pin contests and clean up. We couldn't have done it without you!

Our sincere gratitude goes to the following businesses, organizations and individuals for their generous donations:

The Mickelson (\$1,300+)

Steven Lebowksi
Bob Mannino

The Nicklaus (\$1,000+)

Kenwal Steel Corporation
Evelyn Kosch-Mannino

The Palmer (\$500+)

Mike & Stella Banich
Anthony Iaquinto
Jem Industries
MAG Automotive, LP
Joe Wisne

The Watson (\$250+)

Daniel & Beverly Buckley
C. Hawker & Associates
Mr. Joe's Sports Bar
Ray Lalli
OK Foods
Martin Seward
U of M Fragile X Clinic
John & Nancy Warneck

The Player (\$150+)

Advantage/Waypoint
Arnaldo's Banquet Center
Florence Coleman
(In Honor of Richard)
Escalon Premier Brand
Tomatoes
Family Dentistry, PC
Fontanini Meats
Green Lantern Pizzeria LLC
William & Kim Holdsworth
Raymond James
Kiwanis Club Of Allen Park
Kelly Koson
Lakeshore Utility
Gary & Donna Lebowski
Liberati's Italian Deli & Bakery
Liberati & Sons Construction
Mama Rose & Papa Liberati
Lincoln Park Community
Credit Union
Mama Rosa's Pizzeria
McInerney's Chrysler Dodge
Jeep
The Orchards Golf Club
Pia's Restaurant
Richard Plawecki
Pomponio Construction
Rivers Edge Financial
Rony's Body Shop, Inc.
Roselli Foods
Charlie & Inez Roy
Sartori Company
Silverton Skin Institute
Sorrento Cheese Co
Theresa Sternicki
Telegraph Chrysler, Dodge,
Jeep, Ram
Kenneth Vance
James & Cindy Vickey
David Wujczyk
The Wurth Family

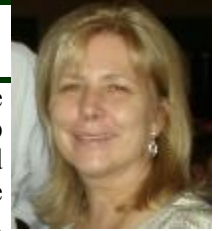
We would also like to thank the following businesses, organizations and individuals for their donations and/or time:

Terry Adams

Advantage One Federal Credit Union

Anoir Agemy
Anthony Aratari
Bob & Pat Asmussen
Cathy Bartolotta
Mr. Jim Beri
Dr. & Mrs. John Bernat Jr.
Karen & Jerry Bishop
Dr. Martha Carlson
Bill & Shirley Cavataio
The Cohen Family
Florence Coleman
Nick & Jennifer Coleman
Rick Coleman
Patrick Duerr, Jr.
JoAnn Forde
Edmund & Nancy George
Chrissy Grybel
Rosalie Guerra
Mr. & Mrs. Hancock
Joe & Sharon Heltsley
Joan Grab
J. Goulasarian Contracting, Inc.
George & Barbara Jakubik
Levon & Gloria King
Tony Kleczynsky
Tony & Maria Lalli
Deborah Lee
Tullio Liberati, Jr.
Ron & Lauren Majeske
Tony & Dora Mangiapane
Stella Marzano
Marty & Lesa Melhorn
Sally Nantais
Kailey Owens
Jerome & Jeannette Pearsons
Grace Pizzo
Walt Pytlak
Austin Sienko
Marlene Sienko
Sue Shannon
Mr. & Mrs. Siwka
Jeffrey Stalcup
Weed Eraser, Inc.
Weight Watchers
Debbie Willard
The Wurth Family
Mr. & Mrs. George Wyckhuyse

From the President's Desk by Laureen Majeske



Happy Fall! This is an exciting time because in November we are having our annual FXAM Board of Directors meeting. We come together as a group and take all of your suggestions and comments and put together a plan for the next year on how we can best serve the needs of the families in Michigan. I know you can look forward to new and exciting things! Thank you to all who participated in our annual Golf Outing, whether as a golfer or sponsor, and for helping us raise a whopping \$18,000! The money will go far in putting in place all of the support and events we will be bringing to you this coming year. We always look for new ideas,

so if there is something you would like to see happen, let us know!

Our Support Group meetings are back in full swing after the summer off. If you haven't been in awhile, come check it out. We take more time to let you in on FXAM plans and we end with social time so attendees can spend time with each other to get more personalized help and develop new relationships. The November meeting will include child care in keeping with our commitment to provide it during at least two meetings per year. Genetic Counseling graduate students from the University of Michigan will once again provide this service. The kids had a great time with them the last

time they were here. Wrapping up the summer, we had lots of fun at the Family Picnic, hosted by Mary Beth and Ted, the Golf Outing, hosted by the Liberatis, a Friendship Circle playdate, hosted by Joyce and Elina, and more. Our Holiday Party will be right around the corner. Look for more details in the newsletter.

Congratulations to our very own Antonio Liberati who was crowned Homecoming King this year after being elected by his fellow high school students! What an honor to know that our kids are making a difference in the world!

Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

We still have several available clinic appointments through the end of 2014 and we have already set up a partial schedule for 2015.

If you are interested in signing up for the FXCRC FORWARD Registry and Database, or would like to make an appointment for any other reason, please contact my direct phone line at 734-615-3591.

We have an exciting upcoming research opportunity here at the University of Michigan! Kate Partynski, a 2nd year graduate student, is studying fathers of children with Fragile X syndrome to learn more about their coping styles and experiences in raising a child

with Fragile X syndrome. Please stay tuned for more information regarding when the survey is ready. Our upcoming clinic schedule is listed below:

U of M Fragile X Clinic Schedule

November 6 and 13, 2014	March 12 and 19, 2015
December 4 and 11, 2014	April 16, 2015
January 15 and 29, 2015	May 14 and 21, 2015
February 12, 2015	June 11, 2015

Free Childcare at our November 1st Meeting!

6:30 - 9 pm
Free childcare available

6:30 Business meeting

7 - 9 Support meeting

RSVP by October 29 to
mblangan@hotmail.com with
your children's names and ages

We'll have food & fun caregivers for them!

Please bring something fun to share (game, toy, coloring book...).

Hope to see your whole family in November!

"A flower does not think of competing against the flower next to it. It just blooms."

~ Author unknown

eXtra, eXtra

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FXAM.org



Tania and her Knight in Shining Armor

See page 2 for the full story.



Photo courtesy of Len Woods



Photo courtesy of Len Woods

 **Fragile X**
Association of Michigan

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