

**Mark Your Calendar**

**Support Meetings**

First Saturday of the Month

*When:*

**February 1, 2014**  
**March 1, 2014**

**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:**

**March 4-5, 2014**

**Advocacy Day**  
Washington, D.C.

**July 16-20, 2014**

**14th International FX Conference**  
Orange County, CA

**Fragile X Association of Michigan**

Contact Information:

**313-381-2834**

**FXAM.org**

A member of the

**NFXF LINKS Network**

(Linking Individuals  
Nationally in  
Knowledge and  
Support)

**Three Cheers for...**



**Antonio Liberati** - Antonio won an award for Most Enthusiastic during the Fall 2013 sessions with Wayne State University's Athletes with Autism (see page 5 for more info).



**Henry Ohnui** - After Henry's first professional haircut from Carnival Cuts at Lakeside Mall.

**Austin Nantais** - In December, Austin developed Hemolytic Anemia. He spent 15 days in the hospital and had to have his spleen removed. Through it all he was a real trooper.



**Snow Days!**



Snow pants on and ready to play!



Maggie & Patrick at Alpine



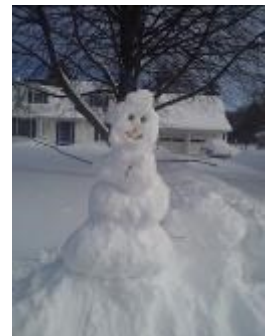
Riddick loves Chuck E. Cheese on a snow day!



Family time at the Gelfands'.



Coco, Sammi & Jake



By Ryan & Rachael

## Apps for iDevices (iPhone, iPod, iPad, and much more) Apps for Autism - Autism Speaks [autismspeaks.org/autism-apps](http://autismspeaks.org/autism-apps)

The holidays are over and now you have that new device and you're overwhelmed with what apps would be the best fit for your child or adult.

We have two recommendations:

1. Check out the "Autism Apps" webpage from Autism Speaks.
2. Check out our feature column, "Apps for iDevices" in previous newsletters on our website at: [fxam.org](http://fxam.org).

### Apps for Autism

On the "Autism Apps" webpage - [autismspeaks.org/autism-apps](http://autismspeaks.org/autism-apps) - as a default, apps are listed in alphabetical order. You can filter the apps by:

- What does it do
- For what ages
- On what device
- Or search by keyword

You can also sort the Apps listed by the way they are rated by clicking on the "Rating" link above the rating column. Later to switch back to alphabetical order simply click on the "Name" link above the App Name column.

You can rate apps by first clicking on the app name to visit the app detail page. Then, below the description of the app, click on the number of stars for your rating of the app.

Apps now have a research rating:

- Anecdotal = No specific or related scientific studies for this type of app.
- Research = There are some related scientific studies, but no direct research support for this type of app or technology.
- Evidence = There is solid or specific scientific evidence

that this type of app or technology is helpful.

### Apps for iDevices-FXAM

To quickly identify which FXAM newsletters had the "Apps for iDevices" column, go to the FXAM support page where newsletters are found, select the "here" link for a list of topics covered in previous newsletters.

Does your child have a favorite game, app, PC software that you believe other children/adults might enjoy? Please share and send your review to the editors for inclusion in a future newsletter.

Mary Beth  
[mblangan@hotmail.com](mailto:mblangan@hotmail.com)  
 Sally  
[sallyn423@wyan.org](mailto:sallyn423@wyan.org)



**Learn more and register at:**

[fragilex.org/advocacy/advocacy-day/](http://fragilex.org/advocacy/advocacy-day/)

FXAM offers a scholarship to help ease your budget if you'd like to participate in the NFXF Advocacy Day in Washington, D.C. This year, the event is March 4-5.

If you are interested in attending and would like to apply for the scholarship or for more

information, please contact  
 Laureen Majeske at

[lmajeskel@comcast.net](mailto:lmajeskel@comcast.net) or  
 586-978-9079

by **Monday, February 3**, stating your intention to apply for the scholarship.

**ad·vo·ca·cy**  
 /'æd və kə si/ Show Spelled [ad-vuh-kuh-see]  
 noun, plural ad·vo·ca·cies.  
 the act of pleading for, supporting, or recommending; active espousal: He was known for his advocacy of the Fragile X agenda.

## Between the Lines - Featured Book

### ***Meeting the Challenge: A Guide to Respectful, Effective Planning, Advocacy and Support with People who Have Puzzling Behaviour***

By Susannah Joyce

Reviewed by Sandra McClennen, Ph.D.

(a licensed psychologist experienced working with FXAM families)

Order online from

<http://www.realizationstraining.com/Resources-from-Realizations.html>

Written for families, friends and paid supports, this book explores behavior through the varied aspects of our shared human needs and experience. It emphasizes understanding rather than controlling.

Joyce reminds us that we need to presume competence and that what we call “behavioural challenges” has a rational or biological reason. Anecdotes, often from her own experience, promote understanding of her approach.

She calls for a team approach. She encourages developing circles of support for people. She reminds us of how easy it is to be unintentionally cruel by not constantly comparing our actions to our values.

She addresses the language that we use – not just “person first” language, but the terms that drive me crazy – compliance, manipulation, mental age, high-functioning/low-functioning, and readiness – to name a few. There are more, and Joyce has included all that are on my list and a few that I have added to my list.

Those who read this review almost certainly believe in these values. Joyce’s checklists, questions, reminders give us tools to keep ourselves on track and to teach others. For example, she suggests using a biographical timeline to develop compassion for those whose lives have been chaotic, unloved and controlled by others. Reading some of the examples certainly sheds light on those people’s puzzling behaviors.

Joyce quotes Dr. Ruth Ryan extensively, addressing identification of physical problems, pain, nutrition, and medication. People with a developmental disability can also have a mental health problem that needs to be identified and addressed. Joyce gives many examples of the value of counseling and therapy, both individual and group.

There is a chapter on trauma that is very inclusive of the types of trauma that might have been experienced by a person with “puzzling behavior.” There is a section on the experience of grief and grieving.

For every issue she brings up, Joyce makes helpful suggestions. I recommend this book for everyone who has a family member or a friend with a developmental disability and puzzling behavior and for all whose professions bring them into this group of people. Not only is it a good reminder for all of us, but it is an excellent book to share with others to help them understand our point of view.

*In the long history of humankind (and animal kind too), those who learned to collaborate and improvise most effectively have prevailed.*

*- Charles Darwin*

## Sharing our eXcellent resource info

*FXAM member Kim Young recommended a new feature column for our FXAM newsletter. We have such a wealth of knowledge and experiences in our group - from new and not-so-new members. Let's share our resource info with each other in this format so members who can't attend meetings can also participate.*

*We would like this to be member driven. Do you have a program that your family member absolutely loves? Do you have a resource that you have used that has helped you help your child be their best? Have you had an experience that you could share with others that may assist others in our FXAM family? What are your tips and*

*tricks? You might have resource info based on a specific age group (Early Development, Elementary, Middle School, High School, 18 & over) or a specific topic which may or may not span different age groups (sensory needs, homework, sleep issues). Please share your knowledge! Sally kicks off the column below.*

### Theme: Beginning Planning for 18 and Over

By Sally Nantais

When your child turns 18, legally he/she becomes an adult and by law will be responsible for all medical, educational and financial decisions. It is critical that parents understand what it means not to have a Power of Attorney (POA) or Guardianship in place.

As noted on the cover page, Austin was hospitalized in December and without our POA, I would have not been able to make any decisions on his behalf. Within the first 24 hours, I needed to provide consent for a blood transfusion. He had five while he was in the hospital and without the blood transfusions his Hemolytic Anemia would have been fatal.

Our first signs that a serious health issue was going on was when Austin turned jaundice. We immediately got into a doctor appointment and when the doctor mentioned it could be his liver, spleen or pancreas we went directly to the ER. I had my wits about me at the time and ensured I had a copy of his POA with me (just in case they were unable to pull it up in his medical records).

Now I have created a folder, that I can easily grab, that contains some of his most pertinent medical history and his POA. While in the hospital, I had copies of Austin's Positive Student Profile that I could share with staff which was changing numerous times in the course of a day. I am going to tweak this document to make it more of a Medical Profile and add it to his medical folder. It will still contain information on Austin's strengths and weaknesses, likes and dislikes, but it will translate more to the medical environment. Staff will often approach the patient with questions, often to determine how coherent the patient may be, with a child/adult with a disability this is not an accurate measure. On any given day I'm not sure Austin would know what day it was, and in the hospital all days seemed to run together, I often lost track. When asked his age it could be accurate or it could be way off the mark, we had responses anywhere from 3 years old to 21 years old. A better question for Austin would have been what's on TV (it was always Disney Junior in the early morning and the History Channel for the rest of the day.) They need to understand his sensory needs and do their best to accommodate him, if I'm on hand there is no need to have the IV alarm set to high, they need to ensure I have the ability to silence the alarm (which I often did then using the nurse call button to alert them to the situation), a shared room is not an option, numerous strangers (other patients and their family members) will only increase his sensory overload and anxiety, they need to ensure they reduce eye contact and verbalization if he should show signs of hyperarousal, all things that will be addressed in his Medical Profile.

Within our state there are numerous resources that may help you with the POA or Guardianship process, I recommend you start your exploratory process when your child is exiting the middle school environment.

The Arc can be a valuable resource. Find your local chapter at:

[arcmi.org/chapters/chapter.locator.htm](http://arcmi.org/chapters/chapter.locator.htm)

Michigan Alliance for Families has provided workshops on POA and Guardianship across the state. Check out their calendar at:

[michiganallianceforfamilies.org/upcoming-events/](http://michiganallianceforfamilies.org/upcoming-events/)

Learn more about a Positive student Profile at :

[ecac-parentcenter.org/userfiles/PTI/Tools/Positive%20Student%20Profile.pdf](http://ecac-parentcenter.org/userfiles/PTI/Tools/Positive%20Student%20Profile.pdf)

## From the President's Desk *by Lauren Majeske*



New year, new beginnings, new friends, new challenges to conquer! And many new fresh and fun ideas will be coming your way over the next year. Your FXAM board members are making some exciting new changes to support you in helpful and thoughtful ways. Keep your eye on future email blasts and newsletters as we roll out these new and innovative concepts. Come and be a part of this new year!

On a more somber note, many of you already know about the Davenport family from Georgia who lost their son in a house fire

on January 10. 18-year-old Logan - who was affected by fragile X - died of smoke inhalation; Sheree and her dad - affected by FXTAS - got out of the house in time. It has been amazing to watch the fragile X community come together to support one of their own. At press time, over \$21,000 had already been collected for the family to help with funeral costs and other expenses. Fragile x families and groups from around the world donated to help a fellow fragile X family. The Fragile X Association of Michigan made a \$500 donation to this effort and

many of our members made individual donations as well. One of the best parts of being on this journey together is the sense of community and family support that is offered to people affected by fragile X. The commitment to each other is bonded by shared experiences, knowledge and understanding. Your Michigan family supports you and we support each other. Take this year and make a difference. See you at the next meeting.

## Greetings from the University of Michigan Fragile X Clinic!

By Kailey Owens, Clinic Coordinator

Happy New Year! We hope you all had a safe and enjoyable holiday. We are looking forward to seeing new faces in our clinic this year. Our clinic schedule for 2014 is included. Also, if you haven't yet joined the FXCRC FORWARD Registry and Database that our clinic is participating in and are interested in doing so, please contact me at 734-615-3591. More information on the Registry and Database can be found online at [fxcrc.org](http://fxcrc.org).

We are still waiting to hear from the pharmaceutical company with whom we've been in contact regarding a potential future clinical drug trial at the University of Michigan. We will let you know when we have additional information.



January 9 and 30	July 10 and 24
February 4 and 20	August 7 and 21
March 6 and 20	September 4 and 11
April 3 and 17	October 2 and 16
May 1 and 15	November 6 and 20
June 5 and 19	December 4 and 11

## Wayne State University's Athletes with Autism

Antonio Liberati just completed another set of sessions with WSU's Athletes with Autism. You may want to check out the website if one of your children might enjoy this too! Antonio participates in their Multi-Sports Overview Sessions which includes

playing soccer, badminton, tennis and basketball. Students from the WSU Communication Sciences and Disorders Department work with the athletes to help expand their communication and social skills in the context of sports.

Visit  
[athleteswithautism.org](http://athleteswithautism.org)  
for more info!

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[FXAM.org](http://FXAM.org)



The 14<sup>th</sup> International Fragile X Conference is a five-day educational opportunity for families impacted by fragile X, and for professionals – physicians, scientists, clinicians, therapists and educators – from the fragile X and intellectual disabilities fields. The event will be held at the Hyatt Regency Orange County. Online registration opens March 3, 2014; register at [fragileX.org](http://fragileX.org). Stay tuned for future news outlining FXAM's scholarship opportunities for the conference!



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