

Three Cheers for our Kindergarten Graduates ...



Maggie Branch

Beverly Elementary, Beverly Hills
Favorite subject: Music Class
Future plans:
Professional Swimmer



Paul Fodor

Nowlin Elementary, Dearborn
Favorite subject: Recess/Gym
Future plans:
NASCAR Driver/Computer Game Tester



Genevieve Nantais

McKinley Elementary, Wyandotte
Favorite subject: Group time
Future plans: Monster Truck Driver



Tyler Sutherby

Hedke Elementary, Trenton
Favorite subject: Reading Buddies
Future plans: Fireman/School Bus Driver

Life 101 Graduate – Meet Jason Zarycki by Evelyn Zarycki

Jason is 34 years old and is fully affected by Fragile X. He was not diagnosed until he was 19 years old when the gene was identified and testing became a little more common.



Jason has lived in an apartment since he was 26 years old. This came after he graduated from the LESA Adult program in Howell, Michigan. Jason's apartment rent is subsidized and he is able to live in a very nice one-bedroom apartment on his own. This is possible with daily support supplied by his mother and staff who prompt him to take his medications, take him once a week grocery shopping, once a month to the barber and whatever necessary doctor and dentist appointments.

Jason attends a daily program 3 days per week for 1/2 day. On Thursdays, he volunteers with the "Meals on Wheels" program, which he enjoys very much. This utilizes his positive personality traits of being compassionate, sociable and helpful.

Among Jason's other passions are University of Michigan sports and all Detroit major league sports, of which he is VERY knowledgeable. He has participated in Special Olympics since childhood. This provides him with additional opportunities for being with friends and feeling successful and learning good sportsmanship. He loves all music and Playstation 2.

Jason has an older brother to whom he is very attached, though unfortunately his brother lives 150 miles away with his growing family. Jason has a good sense of humor and his family is very proud of his progress. ✕✕

From the President's Desk

By Lauren Majeske

With the end-of-year school activities, IEPs, graduations and field trips, it is nice that summer is finally here. I appreciate being able to take some time with my children without always rushing around. I hope all of you are finding some time for yourselves and your families as well.

At April's meeting, Jamie McGillivray, M.S., B.C.B.A., Limited Licensed Psychologist and Clinical Manager at the HOPE Center gave us an informative talk on the behavior technique called Applied Behavioral Analysis or ABA. Information on ABA is available at www.beaumont hospitals.com/hope.

Allison Cohen, a beautiful teenager, joined us in May to talk about what it feels like to have fragile X syndrome and a brother who also has fragile X syndrome. She was wonderful allowing us to ask questions, including questions that were personal for her. We appreciated her insight and honesty.

In May, we held a fundraiser at Joey's Comedy Club in Livonia. Mark and Malinda Popejoy were instrumental in arranging "Comedy For A Cause" bringing along many friends from the Ford Wayne Stamping Plant to support us. A 50-50 raffle was held and the gentleman who won kindly donated the money back to FXAM. We raised over \$1,600. Thanks to the 150 people who attended!

Rein in your summer by attending our "Wild Animal Safari" Annual Family Picnic on July 24, at Fort Fraser, in Fraser. The children will be able to enjoy a great playscape and the adults can sit comfortably under a pavilion overlooking the play area. We can fit 100 people under the pavilion, please plan on attending rain or shine!

In August, I hope you can join us at our 6th Annual Golf Outing/Fundraiser at the Wesburn Golf and Country Club. I'll do anything for the cause nearest and dearest to my heart, including pretending to golf, just watch me hit the trees! It's a fun time for all, so I hope you can make it!

Sensory issues with carriers and those affected by fragile X syndrome can be a lifelong learning experience for many of us. My children have benefited for many years from the techniques and knowledge of Sandy Glovak of Sensory Systems. I hope you enjoy Sandy's article and this issue of eXtra, eXtra, which focuses on sensory integration information. XX

Workshop Review

By Cassie Hale

I had the pleasure of attending the Out-of-Sync Child one-day workshop in Royal Oak, Michigan sponsored by The Abilities Center, Judson Center and Children's Therapy Fund.

The main speaker was Carol Stock Kranowitz, M.A., an internationally acclaimed speaker and author of several books, videos, audiotapes and manuals on Sensory Processing Disorder or Sensory Integration Dysfunction (DSI). The main topic was her book "The Out-of-Sync Child Has Fun" as well as learning more about the tactile (touch), vestibular (movement) and proprioceptive (body movement) senses and how they all interact and relate to each other.

Kranowitz was a wonderful speaker - full of energy and a joy to have seen. I couldn't help but think how great it would be to have a grandma like her. She demonstrated many of the fun, easy, inexpensive activities she has in her books as well as ways to put your own personal spin on the activities to make them fit your child's unique abilities. The key was to put excitement into even the simplest of activities to make it fun for kids. I learned many things that I can use not only with my FX son Brentan but with his twin brother as well.

No matter where kids fall on the developmental ladder, everyone can benefit from the activities. There was a lot of valuable information at the workshop but some of the main points I took home were:

1. Remove almost all battery-operated, plug-in and flashing games and toys from your child's daily activities and save them for special occasions or rewards for good behavior or lack of bad behaviors.

2. Heavy work is great for kids and they enjoy doing it. Children need and thrive on heavy work and whether it's moving sand, carrying heavy bags, weighted vest, or sweeping water puddles, all heavy activity is not only fun but helps their sensory system.

3. Crawling is very important to developing a healthy sensory system. Many children crawl very little or skip right over it. Any activity you can do that gets your child crawling (no matter what the age) is good. Kranowitz's book has ideas for making tunnels or doing things as simple as playing Follow the Leader but making it physical with crawling, tumbling, jumping, etc.

There are also a lot of really good ideas for tactile activities such as putting sticky, slimy things in a bowl to touch or putting it in plastic bags for the really tactile defensive kids so all can participate. Just remember the more fun you make something, the more excitement and energy you put into each activity, the more enjoyment your child will have. Don't be afraid to be as crazy and silly with the activities as you can. Your child will pick up on the energy and excitement and drive the activity for you.

I really enjoyed the workshop and highly recommend getting a copy of the book "The Out-of-Sync Child Has Fun". ✂✂

Through the Maze Featured Website

Developmental FX

www.developmentalfx.com

Developmentalfx.org is the website for Developmental FX – The Developmental and Fragile X Resource Centre, which is a not-for-profit organization helping families affected by Fragile X Syndrome and other neuro-developmental disorders.

Developmental FX was founded by Sarah (Mouse) Scharfenaker, MA, CCC-SLP and Tracy Stackhouse, MA, OTR, a Speech Pathologist-Occupational Therapist team well-known in the Fragile X world.

Another FX expert, Marcia Braden, PhD, licensed psychologist and special education consultant, is now part of their team. The team's services include consultation and treatment at their office in Denver or in your area with your family or at your child's school.

The website offers information on Fragile X, neurodevelopmental disorders and sensory integration, along with more information about their organization and services.

The Coffee Talk section, a compilation of columns Tracy and Mouse have done for the National Fragile X Foundation Quarterly newsletter, is a must read. ✂✂

Between the Lines Featured Book

The Out-of-Sync Child has Fun

by Carol Stock Kranowitz, M.A.

The Out-of-Sync Child Has Fun is the follow-up to Carol Stock Kranowitz's The Out-of-Sync Child, a highly regarded book about Sensory Integration Dysfunction. The 2003 follow-up has over 100 playful activities that Kranowitz's labels SAFE – Sensory-motor, Appropriate, Fun and Easy – for children with sensory issues. These activities may seem like fun and games, but they'll also help your child strengthen their sensory system, a system commonly affected by Fragile X Syndrome.

The activities are organized by chapter headings corresponding to the part of the sensory system which can be helped by that group of activities, such as Touch (The Tactile Sense), Balance and Movement (The Vestibular Sense), Body Position (The Proprioceptive Sense), etc. The book also includes four chapters of activities for these sensory-related skills: oral-motor skills, motor planning, fine motor skills, and bilateral coordination and crossing the midline. There's a lot of information in this 300+ page softcover book that sells for \$14.95.

Many of the SAFE activities use typical household ingredients and offer specific instructions plus the list of benefits of the activity for your child.

Not full of hard-to-digest theories, The Out-of-Sync Child Has Fun is a seriously helpful book that can also be fun for the parent! ✂✂

Additional Sensory Integration (SI) Resources

www.abilitiescenter.com - Website for a large, state-of-the-art therapy clinic in Metro Detroit.

www.dearbornspeechandsensory.com - Speech and Sensory Integration Therapy, SE Michigan area.

www.sinetwork.org - Excellent informational site.

www.out-of-sync-child.com - Website has workshop listings and links to numerous sensory resources sites.

Fragile X and Sensory Integration

By Sandra Glovak, OTR

Children with Fragile X have widely varying abilities, but one of the things that they all seem to have in common is dysfunction of sensory integration, sometimes affectionately known as DSI. During my twenty years plus of practice, I must say that the children with the most severe DSI seem to be those labeled as Fragile X, even beating out autism for this dubious distinction. Sensory integration is a theory from the field of occupational therapy that, in part, looks at how sensory processing affects behavior. Let's look at a few examples:

1. When Joseph came in for an evaluation, he banged his head on the tile floor, a behavior the parents saw frequently at home. The occupational therapist assessed Joseph and found him to have a low sensitivity to touch and pain. She was able to give him a home program to help normalize his sense of touch so that when he hit his head on the floor it hurt. The banging stopped.
2. Rebecca was in constant motion. She craved spinning and swinging but was very unsafe with movement through space. Because her body awareness was poor and balance was deficient, she was unsafe on the playground and frequently got hurt. It was also doubtful she would ever learn to cross the street safely. In therapy, Rebecca had lots of fun with playing on moving equipment, satisfying her drive for more information, and the therapist worked on improving her awareness of body position in space through heavy work activity. Rebecca improved in her ability to play on the playground with other children and no longer needed a paraprofessional to stand by her during recess.

While there are many subtle DSI problems that may affect areas such as self-care and

academics, children with Fragile X usually have very obvious sensory processing issues. They may have problems with over sensitivity or under sensitivity, or even exhibit both at the same time. Signs of difficulty with sensory processing may include:

Tactile (Touch)

- Resists haircuts, nail cutting
- Bothered by some clothing
- Difficulty with eating some textures of food
- Responds negatively to unexpected touch
- Constantly touching objects or people
- Decreased or increased pain sensitivity

Movement (Vestibular)

- In constant motion
- Spins/rocks self
- Movement craving interferes with activities
- Restless in school
- Falls easily
- In-coordinated
- Fearful of unexpected movement

Information from Muscles and Joints

- Prone to injury
- Does things too hard
- Throws objects/slams doors
- Difficulty holding a pencil or utensil
- Overly excited by movement
- Unsafe with movement/craves falling

Auditory

- Covers ears with hands
- Distracted by sounds
- Bothered by unexpected sound
- Noise making behavior
- Does not respond when name is called but you know hearing is okay

Visual

- Decreased eye contact
- Visually distracted by moving objects
- Cannot attend if someone enters the room
- Over sensitive to some types of lighting
- Prefers wearing a hat, having eyes covered or wearing sunglasses in most settings

Smell

- Smelling objects or people
- Smelling of food before eating it

Children with Fragile X are usually quite responsive to occupational therapy using a sensory integrative approach. This may involve having an evaluation, following recommended home programs or even weekly therapy sessions. Sometimes even making a few changes in the child's environment such as putting a sound conditioner (wave machine, etc.) in their bedroom so they can sleep through the night (and you can too!) will make a remarkable change in everyone's quality of life.

Of course, Fragile X is not just about sensory processing problems and neither is sensory integration. It looks at far more areas than most people are aware. That is why we have an extensive feeding program, Active Listening Program, Bike Clinic, techniques to improve sequencing and motor planning, handwriting, fine motor and Integrated Play Groups which incorporate sensory integration and community socialization.

Many families have questions about a technique we use at the clinic called Craniosacral Therapy. While we use it primarily to calm and focus children prior to their sensory integration treatment session, we also have some unique ways in which to use it for those diagnosed with Fragile X. As many of you are aware, there is a tendency of the head to narrow and elongate during adolescence. We attempt to use Craniosacral Therapy to minimize this elongation.

Sandra Glovak, OTR is a registered occupational therapist and director of Sensory Systems Clinic, P.C. in St. Clair Shores, Michigan. She has been working (and playing) with children and their families since 1976. Sandy has extensive training in evaluation and treatment of sensory integrative dysfunction, Craniosacral and other manual therapies and Samonas Sound Therapy. She can be reached at 586-293-7553 or sensoryclinic@aol.com. ✕✕

All materials provided on sensory integration are for informational purposes only and do not represent an endorsement by the Fragile X Association of Michigan.

Additional Reference Books

[Building Bridges Through Sensory Integration](#) – by Ellen Yack, M.Ed. B.Sc. (OT); Shirley Sutton, B.Sc. (OT); Paula Aquilla, B.Sc. (OT). 1998 – Syd and Ellen Lerer. Occupational therapy for children with Autism and other Pervasive Developmental Disorders.

Can be ordered from the Therapy Shoppe at 800- 261-5590 or Amazon at

www.amazon.com

[Sensory Integration and the Child](#) – A. Jean Ayres, PhD; 1979 – WPS –Los Angeles, CA. This book was written by the person who originally discovered, researched and named sensory integration dysfunction. It continues to be very worthwhile for the more intense reader. Intended audience is parents, but also an intense work for professionals.

Southpaw Enterprises 800-228-1698

[Toolbox for Parents](#) – 2001 – Henry Occupational Therapy Services. Booklet of suggested home modifications and activities. The home suggestions include helping transitions, creating a homework environment, etc.

Order through Henry Occupational Therapy Services at 623-933-3821 or

www.ateachabout.com

[Toolbox for Teachers, Parents and Students](#) – 2001 – Henry Occupational Therapy Services. Booklet of activities that is practical and easy to understand. Most attention is given to the classroom. Inclusion based model that benefits all children.

Order through Henry Occupational Therapy Services at 623-933-3821 or

www.ateachabout.com

[Toolbox for Teachers, Parents and Students \(video\)](#)- 2001 – Henry Occupational Therapy Services. Makes the activities suggested in the book come alive and look easy.

Order through Henry Occupational Therapy Services at 623-933-3821 or

www.ateachabout.com

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

Guest Speakers/Special Events:

Jul 24: **Picnic, Fort Fraser**
Steffens Park, Fraser, Michigan
586-294-0450
www.ci.fraser.mi.us

Aug 27: **Annual Golf/Dinner Fundraiser**
Wesburn Golf & Country Club
South Rockwood, Michigan

For an electronic copy of the newsletter,
please visit our website.

Oct 15: **Conference: X-pert Advice**
Fragile X and Autism Spectrum Disorders
Managing Behavior, Education and Stress
Beaumont Hospital
Royal Oak, Michigan

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E-Mail: fraxmich@hotmail.com

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

eXtra, eXtra

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