

Three Cheers for...

The Sixth Annual Fragile X Association of Michigan Golf Outing



Setup with Florence Coleman
(Nina's mom) and Stella
Marzano



Tony Foresi and Frank Pascarella,
ready for some golf.



Randy and Sally Sisk, Bob
Wallace and Sheldon Miller

**Special recognition
for continued support
from our Gold Sponsor**

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Eureka Rd
Taylor, Michigan

**Jim Shingler
and
Pete Ciak**



Arlene and Josh Cohen

Thank You!

Our sincere gratitude also goes to the following sponsors.

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Herman and Judith Zarkis ✕✕

From the President's Desk By Lauren Majeske

Once again, we have had a very busy summer season. The picnic in July was a wonderful gathering, the rain stopped just in time. We had numerous families join us at Fort Fraser for a day of fun and games. The children enjoyed the playscape, crafts and scavenger hunt.

In August, we held our annual golf fundraiser. Over 125 individuals participated and luckily the rain stopped just in time for this event too! Our attendees took home a goodie bag filled with treats and a golf shirt. Everyone enjoyed a great day of golf and a fabulous dinner. Many, many thanks to our sponsors and all of those who have graciously sponsored us over the years.

Our business meetings are held at 6 p.m., right before the support group meetings on the first Saturday of every month. Business and support meetings are open to anyone who wants to attend. This is where you can find out and participate in the planning of future events. Whether you want to just listen, participate on a committee or just put in your two cents, anyone and everyone is welcome to attend. We have many dedicated families, but there is always room for more, including you. Please join us! ✕✕

Through the Maze Featured Website

Speechfun

www.speechfun.com

Speechfun is a website hosted by two Florida women – a speech pathologist and a parent of a child with autism. It offers “supplemental software for the classroom and home” for parents, teachers and therapists.

The offerings change often and are free, free, free! They have activity sheets, 2.5” PECS cards, sign language cards plus an excellent page with great links to other sites helpful in improving a person's speech, language and communication. Check it out! ✕✕

Additional Resources

www.pecs.com - The company which created the Picture Exchange Communication System (PECS).

www.promtinstitute.com - Information on PROMPT, a speech therapy method recommended for some children with fragile X. The site includes good links, resources and offers a means to find a local SLP who is trained in PROMPT.

www.mayer-johnson.com - The company which created the Boardmaker system using Picture Communication Symbols (PCS).

www.superduperinc.com - It's a great catalog/connection for speech/language information.

Between the Lines

Featured Book

Words Are Not for Hurting

by Elizabeth Verdick

Words Are Not for Hurting is just one of a wonderful set of board books. They can be read to non-readers or read by early readers. In simple terms, all of the books teach the important lessons stated in their titles.

The other books are Hands Are Not for Hitting, Teeth Are Not for Biting, Feet Are Not for Kicking and Tails Are Not for Pulling. Germs Are Not for Sharing will also soon be available.

All of these books plus many more interesting items for children and teens are distributed by Free Spirit Publishing (www.freespirit.com). Words Are Not for Hurting and some of the other books are also available at Target and other stores. ✕✕

Speech, Language & Communication

by Leonard Abbeduto, Ph.D.

Follow a child or teenager around for a day and you'll learn that language is central to virtually every encounter with the world. Much of what is taught in school involves adults and peers presenting information orally. Participating in games on the playground requires using language to invite others to play or to request "admission" to an ongoing game or group. Even getting food at lunch typically requires using language. For many youth with fragile X syndrome, however, learning to use and understand language is a great challenge, and for some affected children, spoken language is completely beyond their grasp. These limitations in the language arena make navigating daily life immensely more challenging. It is absolutely critical, therefore, that families and professionals work together to understand the challenges and strengths that each youth has in language so that they can devise ways to foster further language development and help the youth maximize whatever language skills he or she has.

My colleagues and I have spent the better part of 25 years trying to understand the language challenges facing youth with developmental disabilities, and the past eight years or so have been focused largely on fragile X syndrome. We have learned a good deal about the language challenges and strengths of youth with fragile X syndrome, and I am happy to have the opportunity to share some of our findings. Before I do so, however, it's important to recognize that there is incredible variability among children with fragile X syndrome as regards the severity and nature of their language challenges. See "The Scope of Speech and Communication with Fragile X." in this newsletter. So, although our findings "fit" many youth with the syndrome, they do not apply to all. In our own

research, we've worked mainly with children and adolescents who can speak using phrases or sentences. From a practical standpoint, these findings provide a starting point for thinking about the assessment and treatment of any child or adolescent with fragile X syndrome, but a good clinician will dig much deeper to understand the unique needs of the individual. So, with that rather lengthy preamble, here are a few things that we have found.

- Learning a language – in the sense of learning what words mean and the "rules" for combining those words into phrases and sentences – is a challenge for many youth with fragile X syndrome, particularly boys. At the same time, however, learning vocabulary and combinatorial rules is often much less of a challenge than is learning how to use those words and rules to talk and listen in everyday social interactions. This means that any language therapy that relies on flashcards or other highly didactic approaches probably won't have much of an impact on a youth's "everyday" speaking and listening skills. The most effective language intervention will incorporate language teaching into meaningful social activities, such as learning how to request desired objects at play, how to greet people, how to ask questions in the classroom, etc.
- Perseveration, or the repetitive use of language, is frequent among youth fragile X syndrome, particularly boys, and it can interfere with full participation in social interaction. We've also learned, however, that perseveration is more likely to occur in relatively unstructured interactions, like conversation, than in highly structured, goal-oriented activities, like describing pictures in a book. In addition, our research suggests that different types of repetition can reflect very different types of underlying problems; for example, repeating syllables over and over again might reflect

difficulties with the mechanics of speech, whereas repeating the same phrase or topic might reflect difficulties in attention and planning. These findings suggest that adding structure to an interaction -- breaking it down into a series of smaller, highly orchestrated steps -- might reduce some types of repetitive language. The findings also suggest that some of the therapies designed for stuttering or word-finding difficulties may be helpful for some types of repetition in fragile X syndrome as well.

- In many respects, communication is simply giving people the information they need. In our research, however, we have found that this is an area of special challenge for youth with fragile X syndrome. These youth, for example, tend to use vague and inconsistent descriptions when describing objects, especially when they cannot rely on gestures, like when talking on the telephone or talking about objects that are not physically present. We believe that parents, teachers, and clinicians can help here by responding to uninformative messages with directives that clearly indicate the information that is missing; for example, "You said you want the hat, but there are lots of hats here. Tell me the color you want."
- Being an effective listener means monitoring your understanding on what is being said so that you know when don't understand or are uncertain of the speaker's intent. In our research, we have found that this also an area of special challenge for youth with fragile X syndrome. They often rush to respond to directions, for example, and fail to recognize that the directions are incomplete or that they have misunderstood them. They seldom ask questions that clarify misunderstanding, like "which color did you mean?" Instead, these youth allow the misunderstanding to "snowball" over the course of an interaction, which means that the interaction is likely to be frustrating to them and to others. We believe that youth with fragile X syndrome could improve in this area if we occasionally tried to "slow them down" (e.g., by saying, "Not yet. Think about what I said first."), if we provide them with corrective feedback when they act without understanding (e.g., "that's not what I said to do."), and if we periodically "test" their comprehension so that we can make their misunderstandings explicit (e.g., "which book did I want you to read?").

We've learned a lot about the language challenges facing youth with fragile X syndrome, and we thank the many families who have participated with enthusiasm and patience. However, there is still a lot that we don't know. Most importantly, we know very little about why some children with fragile X syndrome develop quite good language skills, whereas others end up with very limited skills. This is an issue that must be addressed if we are to provide effective interventions and therapies, and it's the focus of our current research project, which is funded by the National Institutes of Health. If you would like to learn more about this project, please contact me at abbeduto@waisman.wisc.edu.

If you're interested in reading more about our research or about our thoughts on language intervention, I recommend the following articles, although some are rather technical:

Abbeduto, L., & Hagerman, R. (1997). Language and communication in fragile X syndrome. *Mental Retardation and Developmental Disabilities Research Reviews*, 3, 313-322.

Murphy, M. M., & Abbeduto, L. (2003). Language and communication in fragile X syndrome. In L. Abbeduto (ed.), *International Review of Research in Mental Retardation*, Vol. 27 (pp. 83-119). New York: Academic Press.

We've also written some papers on Down syndrome that I think have relevance for understanding and treating language challenges in fragile X syndrome, including:

Abbeduto, L., & Keller-Bell, Y. (2003). Pragmatic development and communication training. In S. Buckley and J. Rondal (Eds.), *Language intervention in Down syndrome* (pp. 98-115). London: Whurr Publishers.

Abbeduto, L., Pavetto, M., Kesin, E., Weissman, M. D., Karadottir, S., O'Brien, A., & Cawthon, S. (2001). The linguistic and cognitive profile of Down syndrome: Evidence from a comparison with fragile X syndrome. *Down Syndrome Research and Practice*, 7, 9-15.

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University of Wisconsin-Madison

The Waisman Center Research Participation Core -- www.waisman.wisc.edu/rpc/

"The Scope of Speech and Communication with Fragile X"

Austin, age 13

- said first words at age 2
- used short two- or three-word sentences at age 4
- loves to perseverate about Halloween & dressing in costumes
- currently uses phrases, "In your dreams!" or "You wish!"

Andrew, age 4

- non-verbal
- has been babbling since very young
- has very few word approximations
- communicates with PECS, signs & gestures

Charlie, age 3

- non-verbal
- babbling since very young
- 2 - 3 words may be emerging
- limited use of PECS & signs
- some use of gestures & prompts, i.e., brings us the remote if he wants to watch TV

Tyler, age 7

- at age 3.5 spoke 10-15 words
- now speaks in phrases & short sentences
- very good at sarcasm
- favorite expression is "Aw, come on!"
- "Fix it!" means change the channel on TV
- mimics everything

Kayla, age 3

- saying a couple words at 34 months
- signing at 18 months; now has approx. 20 signs
- didn't babble much when she was younger

Brentan, age 3

- non-verbal; no word approximations
- at 30 months old said "Mama" for two weeks and then stopped
- communicates with signs & gestures

Isabel, age 14

- spoke at age 3
- the doctor thought she was advanced by the way she could repeat things perfectly and used yes in the right context
- fully verbal and likes to make people laugh
- enjoys talking with adults more than peers
- repeats silly comments heard on TV or in videos

Ryan, age 15

- spoke first word at 16-months-old
- went quickly from speaking 2-3 word sentences to rapid, perseverative speech
- likes to perseverate with questions like "What are you doing?"
- uses lines from comedy movies & mimics voices
- very hard to understand at times due to his rapid speech

Hannah, age 3

- one of triplets
- first word about 18 months old
- babbled very young
- uses language creatively in 6-or-more-word sentences
- talks non-stop

Antonio, age 9

- non-verbal
- uses PECS & signs
- beginning to use an AlphaSmart; is enjoying it and picking it up quickly

Bradley, age 3

- one of triplets
- non-verbal
- only babbles in vowel sounds
- has very few word approximations
- communicates with pictures, a few signs, takes us to what he wants & gestures

Jenna, age 3

- one of triplets
- first word at about 16 months old
- babbled very young
- uses lots of familiar phrases "It's okay."
- uses short three- or four-word sentences
- talks when she needs something or sees something she likes

Nicholas, age 9

- first words at age 3.5
- used short two- or three-word sentences at age 6
- easiest to understand him when he's happy and anxiety-free
- currently uses "Knock it off!" & "MMOOOMM"

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

Reminder: No Support meeting in December and January because of the holiday party and holidays.

Contact Information:

Phone: 313-381-2834

E-Mail: fraxmich@hotmail.com

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

Guest Speakers/Special Events:

Dec 3: Holiday Family Party
Buddy's Pizza, 6:30 p.m.
Details will follow.

Feb 4: Guest Speaker from MPAS
"IDEA 2004 – How it affects Students
with Disabilities"

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.

eXtra, eXtra

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