

**Three Cheers for
Alex and Jakob Louk
and Friendship Circle**



My name is Alex and I have a brother with Fragile X named Jakob. My brother and I love to go to a place called Friendship Circle. Friendship Circle is a place for kids with all types of disabilities. My brother and I have been going to Friendship Circle since 2005. Jakob attends many programs such as Torah Circle, Sports Nights, Life Skills, Cub Scouts and has two high school students come to our house to play with him for an hour on Fridays which is called Friends at Home. I volunteer at Torah Circle, Sib Nights, Life Skills, and sometimes Cub Scouts. The programs provided by Friendship Circle help kids in everyday life and provide opportunities to hang out with new friends. My brother loves going to Friendship Circle and loves his volunteers. I love helping out at Sib Nights because I get to talk and help kids that are going through the same thing as me with having a special needs sibling. Friendship Circle is an amazing place, helps so many people and has changed my life and my family's life so much. We love going there and it's almost like a second home. Friendship Circle has many creative, fun therapy rooms in the upstairs of the building. Life Town and a big gym/multipurpose room is downstairs. Life Town can help people practice skills at a bank, library, pet store, Sav-On Drugstore, nail salon, Henry Ford medical center, movie theater and workshop. It is open to everyone in the community. Friendship Circle is a place where kids can go and just have fun!

Learn more about Friendship Circle at friendshipcircle.com, 248-788-7878 or Friendship Circle West Bloomfield, 6890 W. Maple Road, West Bloomfield, MI 48322. ✕✕

**Students with Fragile X syndrome,
What Teachers need to Know
by Sandra McClennen, Ph.D.**

Fragile X syndrome is an inherited abnormality of the X chromosome. It is the major inherited cause of mental retardation. Children with fragile X syndrome have also been diagnosed as having autism, learning disabilities, and attentional deficit disorders both with and without hyperactivity (ADD and ADHD). Each child with fragile X syndrome has an affected parent. Most of these parents demonstrate none of the characteristics associated with fragile X syndrome to the point that they interfere with successful adult living.

Many of the behavioral, language and attentional characteristics associated with fragile X syndrome are believed to be the result of sensory integration dysfunction resulting from inability of the brain to fully process and/or organize the flow of sensory impulses. A fairly predictable pattern of learning styles and behavior has emerged. The intensity of these behaviors, and therefore the degree of their interference with typical functioning, varies from person to person.

Children with fragile X syndrome present a unique and fascinating pattern of cognitive, behavioral, and affective characteristics. What you think you see is not what you get. Hidden beneath the challenging and often puzzling behaviors caused by central nervous system dysfunction are skills in visual learning, surprising evidence of memory and understanding, a sense of humor, and affection for and need of other people. These are particularly vulnerable children who require skilled assistance based on understanding of their situation in order to express their hidden capabilities.

Cognitive Characteristics and Strategies

Memory: Visual memory is a strength. However, when asked to state facts, anxiety and lack of context interfere. Suggestions: Determine student's knowledge indirectly. Whenever possible, provide a context. Often students can learn to access information rather than have to produce it from memory.

Teach the academic skills of reading (or use of picture lists and directions), arithmetic, and written expression in the context of purposeful accomplishment of tasks that require the skills. Otherwise, the material will be learned as rote exercises rather than as problem solving skills.

Sequencing: Following are examples of such tasks, responses of some boys with fragile X syndrome, and suggestions for assistance:

Task: Follow directions with more than one step.

Response: Student follows the first step of the direction, then stops.

Suggestion: Provide picture or written directions, one per page, and teach the student the process of following the direction on the first page, then turning it over, following the direction on the second page, and so on. This allows the specifics of the directions to change without changing the procedure of using the system.

Task: Follow a schedule.

Response: Student either (a) memorizes a typical schedule and is unable to deal with change or (b) tries to follow the schedule on the board but is unable to find the current place.

Suggestion: Provide an individual picture or written daily schedule, one activity per card, and teach the student the process of checking his schedule for the next activity, doing the activity, then turning the card over after the activity is completed. This allows the schedule to be changed without changing the procedure for following it. See McClennen (1991) for a detailed plan for teaching time management with picture schedules.

Task: Read using phonics.

Response: Student learns to match sounds and letters (especially consonants), but is unable to sequence sounds into words.

Suggestion: Teach a whole-word or word family approach to reading.

Visuospatial skills: Give reminders before transitions. Use photographs of the next activity or environment. Provide a computer or electronic typewriter rather than requiring handwriting.

Math skills: Beginning mathematics is built on the relationships of objects to each other, beginning with one-to-one correspondence. In order to solve problems, the student must perceive the relationships, decide on a course of action, then follow a step-by-step procedure to arrive at a solution. Children who do not have a particular difficulty with typical elementary school paper-and-pencil math instruction are those who can perceive relationships in their "mind's eye," understand the necessary steps, and follow them. However, many typical children need real objects in order to learn about the relationships of objects to each other and the manipulation of numbers to explain these relationships. This need for real objects is particularly true for children with fragile X syndrome. *Math Their Way* or similar program provides activities to develop beginning understanding.

Speech and language skills: Some of the more prominent problems in this area are late language development, poor intelligibility, perseverative speech, and difficulty answering direct questions because of problems with word retrieval and anxiety. A relative strength can be seen in vocabulary skills. Language deficits should not be

considered indicative of cognitive inability. Children understand at a higher level than they can express.

Language provides an important coping skill for some students. A technique called "verbal rehearsal" consists of telling oneself what to do, then doing it. Children with fragile X syndrome can learn this technique through repeated practice: A parent, teacher, or therapist says, "Tell me how you are going to ___," waits for the child to explain, assists the child until he has stated it correctly, then encourages the child to follow his own directions.

Children with fragile X syndrome often have a good sense of humor. Gentle humor can make any activity more interesting. Humor is particularly useful in role play to increase communication and social skills.

Organization: To be organized requires remembering, sequencing, and perceiving necessary objects in relation to each other. These are all typically areas of difficulty for children with fragile X syndrome. On the other hand, when an attempt is made to help the child organize by teaching a specific schedule to organize the day or directions for doing a task, and then a change in plans is required, the child cannot cope with the alteration. Teach students a procedure for using a schedule (so that the schedule can change without changing the procedure) and a procedure for following picture or written directions (so that the specifics of the directions can change without changing the procedure). By focusing on following the procedure, which doesn't change, some students can avoid the trauma they tend to experience from changes in the actual order of events. Picture or word lists with a procedure for using them can be used to teach students to gather materials for a project, for going home, or for getting ready for school.

Procedures for following picture or word lists and directions can be adapted to a wide variety of purposes. The child who has learned to follow these procedures will be able to perform a large number of tasks that he could never do by memory.

Social skills: Social interaction and communication are based on many skills that are especially difficult for children with fragile X syndrome. As a result, the youngsters often appear socially inappropriate. They seem to have few skills in identifying and responding to nonverbal cues. They say things that seem inappropriate to a current conversation. Sometimes, they avoid social interaction, appearing withdrawn or shy.

Social interaction skills can be taught. Children with good social interaction skills are necessary for this process. After analyzing the skills typically used within an environment, provide opportunities for the child with fragile X syndrome to interact with socially adept children under structured circumstances where teaching can take place.

Visual learning: This is a strength. These children respond well to visually presented information. The use of visual cues (for example, pictures, pointing, and demonstrating) paired with a verbal request often results in a

successful response that does not occur from a verbal request alone. Parents often describe great variability in their children's ability or seeming willingness to respond to requests. Careful observation often shows that when the request is given in full sight of the child with a visual cue, the child is much more likely to respond correctly than when only the verbal request is made. Interestingly, sign language serves as a visual (and kinesthetic) cue for some children with fragile X syndrome as they learn to talk. Some preschoolers use sign language before they begin to speak.

Visual cues can be given in a wide variety of ways. A colored dot or arrow designates the place to begin on the left side of the worksheet. A child's photograph or name identifies his locker. Use the child's response to the visual gestalt. Whenever possible, help the child see the goal.

Imitation skills: Modeling is the term used when an action is demonstrated for the student to imitate. Skill in imitation is a strength for children with fragile X syndrome. Their imitation ability builds on their strength in learning through visual cues and also on the children's positive interest in others. Visual learning and imitation skills enable children with fragile X syndrome to learn a wide variety of tasks that are necessary for independence in daily life and that are needed for many jobs.

Because children with fragile X syndrome have this strength and will imitate those around them, it is important to consider their role models. They will imitate the children who are their daily companions. Thus, if they are with children who demonstrate atypical or problem behaviors, they will imitate those behaviors. If they are with children who demonstrate appropriate behavior, they will imitate that.

Difficulty with Fine Motor Skills: Children often have subtle fine motor difficulties. When a child's handwriting is very poor, or when he tries to avoid writing, consider a keyboard (typewriter or computer) as an alternative. It may result in a great deal more learning and a great deal fewer problem behaviors. When a child has to expend a huge amount of energy just to get information down on paper, there is little left for learning. These same children may have great difficulty with cutting, drawing, and so on. Look for alternative ways that they can participate.

Concrete vs. abstract thinking: Available evidence suggests that children with fragile X syndrome perform better when they are dealing with concrete rather than abstract tasks and materials. Cognitively, children must learn to cope with the concrete world before they can learn to respond to abstractions. Given the challenge of learning to locate themselves in space, the positive response of children with fragile X syndrome to visual learning and imitative modeling, combined with their difficulty in verbal expression, sequencing, and organization, their need for the concrete is not surprising.

These children often demonstrate very specific (and sometimes narrow) interests. Whenever possible, that interest should be used in the service of instruction.

Many people with fragile X syndrome demonstrate a sense of humor. Parents often report that their children derive a great deal of enjoyment from slapstick humor, which is usually literal and concrete.

Skills for solving life's little problems: We often teach people as if each day will progress perfectly. In reality, life is full of glitches—the little things that go wrong daily that must be dealt with. Shoelaces break. Your favorite cereal has run out. Interventions need to be developed to teach people with fragile X syndrome how to deal with the glitches of life so they will not constantly be overwhelmed by them. Interventions include learning to buy an extra before the product you use has run out, substitution and replacement (for example, selecting a different pair of shoes when the laces have broken on one's favorites, then buying new shoelaces), and calling the relevant person when a bus is missed resulting in late arrival.

Behavioral Characteristics and Strategies

Common behaviors and anxiety: Common behaviors, such as hand biting and flapping, gaze avoidance, tactile defensiveness, and perseverative speech, show a marked increase at times of high anxiety. At such times, learning is not likely to take place. The child needs to lower his anxiety, whether through calming, removing himself from sensory overload, or some other means. Sometimes, such behaviors tell teachers or therapists that the adult's requests are inappropriate and need to be modified.

The environment should be as comfortable for the child as possible. Examples are:

- Fidgeting, as long as it doesn't disturb others, certainly should be permissible.
- Opportunities to move around should be more frequent than for others of the same age.
- There should be much more doing than listening activities.
- Headphones with calming music help block out auditory overload for some children.
- One child is reported to participate in group time by sitting in a rocking chair with a book.
- Develop opportunities for the child to leave the room in a nonpunitive way.
- When a student demonstrates gaze aversion, allow him to sit where he doesn't have to face the teacher all the time.

Dr. McClennen is a Licensed Psychologist with many years experience with children with fragile X syndrome and their families. She is available for consultation and also does Independent Educational Evaluations and behavior assessments and plans. She is available from September through May each year.

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Eight Annual Golf Outing
Wesburn Golf and Country Club

5617 S. Huron River Dr.

South Rockwood, Michigan

(one mile west of I-75, exit 26)

Door Prizes

Raffles

Saturday, September 8, 2007

Registration 12:15 p.m.

Shotgun start at 1 p.m. (four-person scramble)

Golfers: \$90 per person

Includes open driving range before the start, hotdogs and refreshments before and during the round, golf and cart fees, dinner and participation gift.

To use a golf cart you must be a paid golfer.

Non Golfers: \$50 per person, Includes dinner, refreshments and participation gift.

All Donations Welcome

Sponsor a hole for \$150, Lunch for \$250, dinner for \$500

Donations are tax deductible we are a non-profit 501(c)(3) organization

All proceeds go towards RAISING awareness, SUPPORTING research and ASSISTING local families affected by Fragile X Syndrome.

Contact Frank or Nina Liberati for tickets, donations (cash or door prizes) or more information at 313-381-2834 or ninaclare@comcast.net

From the President's Desk

By Laureen Majeske

We need your help with the annual golf outing fundraiser.

I'd like to use this as an opportunity to say thank you to the professionals who took the time to speak at our support group meetings.

Veena Rao, Staff Attorney of Michigan Protection & Advocacy Service, Inc. (MPAS). Veena helped us navigate the new IDEA laws and the Michigan Rules and Regulations that apply to the IEP process. She was a tremendous help to our families and stayed long after to answer all of our questions. For information on MPAS, visit mpas.org or call 800-288-5923.

Clifford L. Weisberg, Senior Partner of The Law Center for Social Security Rights, a service of Weisberg & Walkon P.C., Attorneys at Law of Southfield, Michigan. Cliff gave us important information regarding Social Security laws for individuals with disabilities, a very complex subject. He was very lively and passionate about the subject and actually made Social Security fun -- imagine that! Cliff recommends that if you ever have questions reference Social Security benefits your first step should be to contact their office at 800-832-3471. There are no fees associated with questions via the telephone. Additional information on the Law Center for Social Security Rights is available at ssrights.com

Thank you to both of our speakers for their support and to our families who came to learn about these important subjects.

Hope to see everyone at the Family Picnic. ✕✕

This fundraiser is the key fundraiser which enables us to:

- Sponsor local conferences in which we are able to bring in experts in the fragile X and special needs communities.
- Provide the opportunity to assist families with conference scholarships to help them attend the National Fragile X Foundation International Conferences
- Allows our organization to donate a considerable sum for the purposes of awareness, research and support for families living with Fragile X.

What can you do?

- Solicit donations for door prizes or raffles. Donation letters are available, donations are tax-deductible.
- Volunteer on the day of the event for setup or cleanup
- Sponsor a hole in honor of a child, either as an individual, a family or as a group of family members, friends or another group.
- Create a mini awareness fundraising campaign to solicit money to sponsor a hole, such as a bottle drive, penny drive or pass out canisters to family, friends and neighbors to fill with loose change in honor of your child.
- Post the flyer (available on the web or copy the flyer on the next page) at stores you frequent or on other organization's bulletin boards in which you are involved; consider attaching a picture of your child(ren). ✕✕

Family Picnic and Fragile X 5K Fun Run & Walk

Sunday, July 22, 2007

National Fragile X Awareness Day

Independence Oaks County Park
Twin Chimneys Shelter
9501 Sashabaw Road

(2 1/2 miles north of I-75, Exit 89) 248-625-0877 (park)
oakgov.com/parksrec/ppark/independence.html

Quote for the Quarter

It takes a village to raise a child.

African Proverb

Mark Your Calendar

Support Meetings:

When: May and June

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 22: Annual picnic and first Fragile X
5K Fun Run & Walk
Independence Oaks, Clarkston,
Michigan
oakgov.com/parsrec/ppark/independence.html

Sep 8: Annual Golf/Dinner Fundraiser
Wesburn Golf & Country Club
South Rockwood, Michigan

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.

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