

GREATER CLEAR LAKE Families Exploring Down Syndrome

Calendar of Events

Monthly Meetings:

6:30 pm Pizza & talk
7:00 pm Speaker
United Way-Bay Area
1300 Bay Area Blvd.
Conf. Room A.
Child care provided.

May
21 Writing IEP Goals:
Joanie Garro,
MA, BCBA, CT

June
16 Community
Resources:
GCLFEDS Board
Members

July
16 Taking Care of
the Caretaker:
Carmen Dick-
erson, TCH
Meyer Center/
DS Clinic social
worker

Events:

May
1 Golf Tournament
8:30am tee time
Magnolia Creek
Golf Course

16 May Social
3 to 6 pm
Challenger 7 Park
Bring a dish to
share

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Seminar Gives Parents & Educators Tools for Teaching Children with Down Syndrome By Anne Bernay

My son, Peter, is a kindergartner fully included in his regular education classroom. He cracks his teacher and I up with some of the things he does. For instance, his attachment to a little girl in his class is precious – resulting in several notes home asking me to talk to him about kissing and when it is appropriate. Then there is the time he covered his classmate’s chair in glue and was sent to the principle’s office. When I asked him why he did it, he signed to me, “to see if he would stick.”

Often Peter’s teacher tells me that his antics are “typical kindergartner boy” behavior. But sometimes, neither she nor I can figure out exactly why Peter does something a certain way or what we can do to keep him focused on his tasks. So I was very interested in attending a recent conference sponsored by the Down Syndrome Support Group of Bryan/College Station called “Teaching Tools for Special Children.” The speaker, Susan Peoples, has been an educator for 30 years, but most importantly has a seventeen-year old son with Down syndrome. I figured that if anyone could shed some light for me, it would be her.

The seminar focused on how an understanding of the ways in which children with Down syndrome (and other developmental delays) learn can be applied to instructional design. In other words, Ms Peoples took research (by National Down Syndrome Society and others), clinical observation and her own experiences and developed specific approaches to teaching children with Down syndrome. Her book Stars of Success (Fort Wayne, IN:



Peter enjoying a party in his kindergarten class.

Special Offspring Publishing, L.L.C.; 2003) was part of our conference packet and summarizes the NDSS Educational Challenges Inclusion Study. We also received samples of the teaching materials she designed specifically for children with Down syndrome.

There was just too much material covered that seminar day to summarize here! However, several topics were of special interest to me and hopefully will give you an idea of what is available through Ms Peoples’ books and materials as well as the NDSS study.

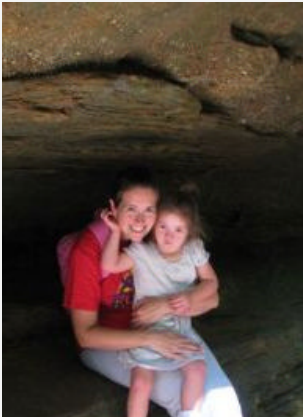
The NDSS Inclusion study outlined six learning characteristics of individuals with Down syndrome:

- 1) Attention
- 2) Memory
- 3) Concept attainment
- 4) Mediation strategies
- 5) Transfer of learning
- 6) Motivation

This article will focus on the first two: attention and memory. These two are

Continued on page 3

GCLFEDS Secretary Alicia Dague and daughter, Anna



A Word from the Sec by Alicia Dague

After another successful Wine Tasting and Silent Auction, the board met in March to discuss, among many other things, our upcoming Golf Tournament scheduled for May 8 and the Spring Social on May 16. Both events were great hits last year!

We welcomed our newest board member, Neesha Hosein, whose work you will see here as she is our Newsletter Editor! We are very fortunate to have her as a part of the FEDS board. Not only is Neesha a very talented writer but she also comes to us bursting with great ideas that will provide fun opportunities for individuals with special needs.

There are some exciting opportunities coming soon through our FEDS library so be watching your e-mails and newsletters for further information. Our librarian, Maria Castillo, in conjunction with our Board is developing a book donation program for our local schools which will allow members to donate books about Down syndrome to the school libraries.

Outreach is a great area in which to become involved. Along with attending Resource Fairs, ECI training sessions and speaking to nurses at area hospitals, they are gearing up for a mass mailing to the medical professionals in the area. If you think presenting information to groups in order to better educate our community is something you are interested in, but feel intimidated – don't – we will train you!

We are excited about providing opportunities to the adult community in our area. We are teaming up with Gloria Dei for a monthly social event. Watch for exciting details to come. We are also looking forward to awarding our first scholarship.

Father's Joy and GCLFEDS are joining up in an effort to better educate our educational professionals with a training program called "Including You." This program will offer presentations to change the attitudes of regular and special education teachers (and parents), training sessions to support educators implementing inclusion and will include a DVD starring local individuals who have been involved in inclusive education. The program is being developed over the summer and hopefully will be ready to pilot in the fall in several school districts.

If you've become a member of GCLFEDS and not yet found a place to get involved now is the time to dive in; just ask one of the board members about exciting opportunities to become involved -- we have so many super things going on! If you've not become a member yet, what's stopping you? Join us, there's something for everyone!

Board of Directors & Committees

If you are interested in helping on the Board or a committee, please contact us at gclfeds@clearlakedes.org

Please contact any of us with suggestions, questions or offers to help!

Board of Directors			
President	Anne Bernay	pres@clearlakedes.org	832-457-2775
Vice President	Open		
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Newsletter	Neesha Hosein	newsletter@clearlakedes.org	
Librarian	Maria Castillo	library@clearlakedes.org	
Webmaster	Joel Burdeaux	joelburdeaux@gmail.com	

Seminar Gives Parents & Educators Tools, continued

Continued from page 1

prerequisites for success in learning and are often recognized as problems for children with Down syndrome but not directly addressed in IEP goals or classroom activities.

The first learning characteristic, attention, was broken into two components: attention span (or the ability to attend to the task) and the ability to identify relevant from irrelevant information. Ms Peoples' said that the first component, attention span, is "the foundation for all future learning" and that this must be trained. I know from firsthand experience that attending to school tasks, especially individual work at his desk, is difficult for my son. In fact, we included IEP goals for 1st grade that focus on increasing his attention to work assignments, starting with 5 and increasing to 10 minutes at a time. It made me feel better to hear that Ms Peoples' seventeen year old son, Michael, is

currently working on reaching 15 minutes.

One of the keys according to Ms Peoples is to reduce distractions. The NDSS study found that the lower the attention span the more susceptible the child is to distractions. She says, "Controlling environmental distractions is an educational starting point." Suggestions for reducing distractions included: 1) placing students in the least distractible seat, 2) remove distracting stimuli such as extraneous pictures on the wall, 3) eliminate visual distractions on the instructional page (increase white space), and 4) be aware of sensory distractions (tactile/auditory/visual).

A second key to improving attention to

task is to train attention. "Never assume that prerequisite learning skills will develop naturally as they do in most typical learners," stated Ms Peoples. She recommended working to increase time on task with "empty content." In other words, practice with your child staying focused on work that is review material or something the child has already mastered. Trying to increase time on task with something the child is just learning causes frustration and is overly difficult.

Memory, the ability to store and retrieve information (upon demand), was the second learning characteristic discussed. Ms Peoples said that the NDSS study found

that short-term memory involves experiencing information and retaining it long enough to put it to immediate use. Short-term memory was found to be heavily based on language labels. Labeling everything in the classroom and using verbal associations are helpful for short-term memory. Repetition and practicing skills in many different contexts and with multi-sensory approaches also aid memory. Long-term memory involves storing information and requires the ability to mentally manipulate the information for retrieval. Showing a child patterns and teaching more sophisticated memory tricks can help children with Down syndrome.

One of the most interesting things Ms Peoples taught about memory involved the concepts of visual and auditory memory, or sequencing. These skills are the ability to sequentially remember multiple pieces of information, visual or auditory,

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Welcome Members!

Welcome New Members

Alexei & Alexis Marchenko – Sawaty age 1.5



Become a member today!

Register online at <http://clearlakeds.org/membership-application/> or mail the form available on the website. Membership has its privileges! Our "Members Only" area has videos of past meetings, a photo gallery and a bulletin board. Members also pay a reduced registration fee for the annual conference.

Thank You Renewing Members

Chris & Lillie Monita – Adrian age 3



Meet Our Member: Wyatt by Tracy Kachtick-Anders

Arlo. His name was going to be Arlo, but when I saw those Downsy eyes and little folded ears, I knew he would be Wyatt, the little warrior. Five and a half years ago, my little man, Wyatt Jack Vida, came into this world on a rare sunny day in Seattle. He was welcomed by two older sisters and three older brothers, all adopted from foster care. Wyatt would be my one and only birth child, a dream finally realized.

In many ways, having other children with special needs prepared me for knowing that Wyatt might have Down syndrome; I figured he would fit right in. What I self-protectively failed to consider was the fact that his issues would include medical concerns, things that were life or death. Within two days of his birth, he had a feeding tube in his nose and the diagnosis of heart defects, hearing loss, hypothyroidism, nystagmus and pulmonary hypertension. He spent five weeks in the hospital and came home to a busy single mom pumping breast milk with one hand, working at the computer with the other and rocking the baby with my foot. Life was back to normal.

Three months later, Wyatt changed my life. He went into congestive heart failure, had a feeding tube sewn into his stomach and was placed on oxygen. He was probably going to die and between screaming while driving, begging gods that I did not even believe in, and imagining myself jumping out of the hospital window, I became strong. A little voice said, "It's going to be okay" and I believed it. I became tougher, spoke up to nurses and doctors and became an



advocate for my child and, in turn, for all of my children. I no longer believed that others were experts and knew more than me. They sent us home a month later with tanks of oxygen and no sense of our future. But we went home brave.

A few years later, Wyatt had open heart surgery and was taken off of oxygen for good. I loved seeing his soft white cheeks free of tape and his ability to crawl around without tubes and wires following him. He soon outgrew his hearing aids and feeding tube.

Things have never been the same since. His heart is beating so strong that he is now considered a little too busy. He runs and jumps and laughs and gets into lots of mischief. He is loving, naughty and funny. He loves Charlie Brown, electronic gadgets and music. With his family, Wyatt lives at the beach, goes camping and loves to travel. Our family recently took a 30-hour bus ride down to Mexico for a three-week trip in a

Meet Our Member, cont.

small Mexican village and two years ago we went on a three-month RV trip across 27 states.

Wyatt does not know he is different, at least not yet. I like that I am doing the dirty work for him right now. I battle school officials, people who want to put him on a special ed. bus for no reason other than having a diagnosis. I write the newspapers, contact administrators and do whatever I have to do to have him treated just like everyone else. I'm happy to say he rides the bus with his brother and sister now. It is the same with his classroom. Those in charge could not imagine why I would want him in a regular-education class when there are programs "just for him." He has proven them wrong. Since being in the regular-education class with children who talk, laugh and sing, Wyatt's speech has increased tremendously. He is having good behavior modeled for him and is learning the basics of the school experience.

Before Wyatt, I would have

sat quietly and let the "experts" treat my children as they saw fit, not questioning their motives or actions. Now I see that it is the mother lions who change the world. We must speak up for those who cannot speak and change outdated ways and beliefs. I believe Wyatt is like a mini-ambassador to the non-disabled world. He changes folks' minds about what and who they thought he would be. Wyatt has motivated me in many ways. For his first birthday, I exhibited an art show just about him, which included paintings, journal entries and information about others with Down syndrome. I also invented The Sleep Tight Wedge for infants who, like Wyatt, use medical equipment or who need to sleep at an angle. Wyatt is the best thing that ever happened to me, and I wish everyone had a Wyatt in their lives!

"...It is the mother lions who change the world."



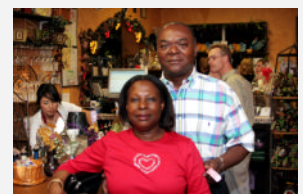
Wyatt and family

Wine Tasting Fundraiser a Success

by Elizabeth Stevens

The 2nd annual GCLFEDS Wine Tasting, held on February 13, at D'vine Wine in Kemah, was a wonderful pre-Valentine's night out and a successful evening of fundraising for FEDS. The event, originally scheduled for September, was postponed due to the disruptive force of Hurricane Ike. By February, Kemah and D'vine Wine were back in business and ready to host an evening in which we tasted great wines, enjoyed good food and conversation and bid on some wonderful silent auction items. D'vine Wine handcrafts its own wines on site from imported grapes and attendees had the opportunity to sample three

of the tasty reds and whites and drink a glass of their favorites. Silent auction items included a Princess basket, a pamper your pet basket, family portraits by Templin photography in Kemah and many other wonderful items donated by our generous sponsors. We thank all the wonderful sponsors, supporters of GCLFEDS who came to the event and the volunteers who helped it go so smoothly. We look forward to next year, and because wine tasting and Valentine's romance go hand-in-hand, look for the event to return in February 2010.



Top: Karen Hall, Kristen Reat & Ellen Lachney
Middle: Board Members Tiffany Novick & Beth Haas
Bottom: Board Member Maria Castillo & husband Robert

Upcoming GCLFEDS Events

2nd Annual GCLFEDS Annual Golf Classic

Friday, May 8

7:30 a.m.
registration/8:30
a.m. Shotgun Start
<http://clearlakede.org/2009-golf-tournament/>

Magnolia Creek
Golf Club
Registration
available at the
door

Please join us and
support GCLFEDS!

GCLFEDS May Social

Where: Challenger 7 Park Pavillion #3

For directions:

www.co.harris.tx.us/comm_lee/PChallenger7/

Time: 3 to 6 p.m.

R.S.V.P. by **May 11** to Beth Haas at 832-689-5961

It's a pot luck party, and GCLFEDS is providing the main dish and beverages! Please bring a side dish or dessert to share. Playground and games for the kids.

Saturday, May 16, 2009

Monthly Meetings

United Way
Service Center -
Bay Area
1300 Bay Area
Blvd.
Room A

6:30 pm
Pizza and informal
parent discussion

7:00 pm
Speakers

Child care
provided.

Upcoming GCLFEDS Meetings

This month, beginning at 7pm, Board Member Joanie Garro will work with us on how to set our IEP goals and provide helpful pointers.

A Board Certified Behavior Analyst and certified Special Education teacher, Joanie has over 20 years experience working with

individuals with special needs and their families as a special education teacher, private therapist and family coach. She currently is in private practice working with families, schools and corporations.

Seminar Gives Parents Tools, cont.

Continued from page 3

together. Up until the age of seven, a person's sequencing skills should match their age. An adult should be able to sequence 7 pieces of information, as in a telephone number.

Children with Down syndrome generally have a lower sequencing ability (or less memory channels) than typical children, which impacts their academic progress. For instance, Ms Peoples says that studies show that children with Down syndrome entering school typically have 3 visual channels and 1-2 auditory channels vs. a typical five year old who would have 5 visual and 5 auditory memory channels. Not only do children with Down syndrome have less channels in total, their deficiency is worse in auditory sequencing. Think about how most teaching occurs in a school. Verbally.

Ms Peoples also told us that sequencing is essential for such tasks as detecting social cues, following a conversation, developing phonetic skills, reading comprehension, following directions, and attending. Behavior, she shared, is greatly affected by memory. Who among us with a small child with Down syndrome hasn't wondered why the behavior issue we addressed just yesterday is back again today?

According to Ms Peoples,

training auditory and visual memory can improve these areas and can be done very easily at home or school. For instance, she recommends such simple activities as asking your child to touch different parts of their body in a sequence or asking the child to find a sequence of items in the room to train auditory sequencing. For visual sequencing, the training is as simple as the memory card game or asking the child to remember a certain number of things he saw on the way to lunch or the gym.

The conference covered the remaining four learning characteristics, but attention and memory were by far the most heavily discussed. With that base established, Ms Peoples presented how physical characteristics of Down syndrome affect learning and how to intervene in these areas to reduce the impact. The last portion of the seminar covered how to design lessons for children with Down syndrome, focusing on reading, writing and spelling.

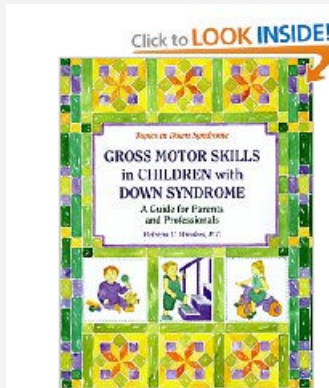
It was an eye-opening day for both the parents and educators who attended, with much practical advice and many 'ah ha's'. Ms Peoples' materials can be found on her website www.SpecialOffspring.com or in the GCLFEDS library.

If you would be interested in hearing Ms Peoples in Houston, please email GCLFEDS at gclfed@clearlaked.org.

Ms Peoples' materials can be found on her website www.SpecialOffspring.com or in the GCLFEDS library.

Visual memory training can be easily done by playing the memory game.





Book Review by Elizabeth Stevens

Gross Motor Skills in Children with Down Syndrome - A Guide for Parents and Professionals

By Patricia C. Winders
(Bethesda, MD: Woodbine House, 1997). Paperback.

One of the most satisfying parts of being a parent of a child with Down syndrome is celebrating the achievement of each milestone. In the first few years of life, we and our children concentrate particularly on achieving the physical milestones, such as head control, rolling over, sitting, crawling and walking. Because therapy sessions are limited in duration, it falls on the parents and family members to continue with what we have learned during therapy to help our children progress. A great tool to help parents in this process is "Gross Motor Skills in Children with Down Syndrome - A Guide for Parents and Professionals."

Written by Patricia C. Winders, a physical therapist who specializes in Down syndrome, the book contains a detailed description of the stages of development of gross motor skills and suggested activities to help children with each stage. The book is divided into two sections, the stages up to walking and the stages after walking. It is filled with detailed descriptions and pictures of activities that further the development of skills such as supported sitting, moving from lying to sitting and taking independent steps. There are

checklists at the end of each chapter, and at the end of the book there are statistics on when children with Down syndrome typically reach 45 specific motor milestones. The statistics were compiled by Winders over a period of 10 years studying 154 children with Down syndrome.

One aspect of the book that I found most helpful was the description of the two types of temperaments – "motor driven" and "observer." The motor driven child is one who loves to move from one position to another, is not afraid of new positions and taking risks and will resist stationary positions such as sitting and standing. The observer is a child who loves stationary positions, such as sitting and standing, and is easily frightened by new positions. These descriptions helped me better understand Claire's ability to sit happily for long periods of time, but her reluctance to move from one position to another. The book contains suggestions for dealing with each type of temperament as you work on the development of motor skills.

For me, this book has been a great companion to the therapy sessions. It provides clarification and further explanation of the concepts involved and the process used to attain the motor skills milestones and has a wealth of practical ideas for helping our kids get from one milestone to the next.

Community Events & Resources

BAYLOR OFFERS MEDICAL CLINIC FOR TEENAGERS AND ADULTS WITH SPECIAL NEEDS

Parents of teenagers and young adults with Down syndrome may want to consider Baylor's Transition Medicine Clinic as they transition from pediatric to adult medical care. The clinic, headed by Dr. Cynthia Peacock, was started in 2005 with the purpose of serving the medical needs of children with chronic conditions as they transition to adulthood. Peacock was a nurse for 15 years prior to entering Baylor College of Medicine in 1991, and joined the Medicine-Pediatric Faculty at Baylor in 2001. She now serves as Medical Director of the Transition Medicine Clinic and is trained in both pediatrics and internal medicine. The clinic provides medical care to patients 14 and up and currently treats patients with a variety of conditions including Down syndrome, autism, congenital heart disease, cerebral palsy, and survivors of childhood cancer. The clinic offers both primary care and consultations. It is located in the new Baylor Clinic located at 6620 Main Street. For more information, social workers with the clinic may be reached at 713-798-0216.



HOUSTON MUSIC THERAPY CENTER COMING TO CLEAR LAKE AREA LOCATION

HMTC is opening the first week of March at the Pediatrics Plus Therapy Services new location at I-45 & Fuqua. They are starting the client waiting list and beginning initial paperwork so that they can hire a therapist for that location. Music Therapy services will be provided by a board certified music therapist to address each individual's target needs and goals through successful musical experiences. ** For more information, please contact: Kate Harrison, MT-BC, NMT Fellow at 713-315-0855 or kate@musictherapycenter.org.

On the practical side, if you are looking for a summer camp for your child, a list of programs for children with special needs is available at www.mikeysplace.net.

SUMMER CAMP FOR CHILDREN & ADULTS WITH SPECIAL NEEDS

As summertime approaches and parents begin looking for summer programs for their children, many parents of children with special needs may find limited recreational opportunities. Children's Association for Maximum Potential (CAMP) offers a summer camp program for special needs children and adults aged 5-45. Campers do everything that regular campers do, like horseback riding, canoeing, outdoor cooking, etc. We offer nine one week summer camp sessions specific to either cognitive or physical impairments at our 55 acre campsite in Center Point, Texas. Siblings aged 5-13 without disabilities may also attend camp, giving parents a break they may truly need. To learn more about Camp CAMP, please visit our Website at www.campcamp.org or call us at (210) 671-5411.

Volunteers Needed!

Join our 2009 Board of Directors and Committees:

- Fundraising Chair: Oversee our fundraising events
- Vice President
- Social Chair: Coordinate our two socials and develop additional activities
- Adult Programs Committee Chair: Design and kick-off our programs for teens and adults

Volunteer to be on a committee:

- Fundraising
- Outreach
- New Parent
- Public Relations

Volunteer to:

- Videotape our monthly meetings and events

Contact

gclfeds@clearlaked.org
or call 832-457-2775 to volunteer.



Sleep Tight Wedge

A Little Inspiration

Karen Gaffney spoke at the GCLFEDS conference last year and showed us that our children can have bright futures filled with accomplishments. People with Down syndrome are accomplishing things in many fields, including the arts. For two examples, check out artists Dylan Kuehl and Michael Johnson. Dylan works in painting and the performing arts. Learn more about him at his Web site www.dylankarts.com and search "DK Arts" on YouTube to see a feature done for the PBS

show Biz Kid\$. Michael Johnson is an accomplished painter who sells his whimsical artwork online at www.loveandlearning.com/michaelpage.shtml.

If your infant has medical issues like reflux or feeding tubes that challenge safe sleeping, consider the invention by one of our own GCLFEDS parents, the Sleep Tight Wedge, at www.sleeptightwedge.com.

We welcome articles and contributions to the newsletter. Send them to Neesha Hosein at gclfeds@clearlakeds.org.

The deadline for submissions to the July newsletter is June 15.

Thank You!

Our 2nd Annual Wine Tasting and Silent Auction event were a great success with many thanks to the following companies and individuals:

Bay Area Houston Ballet & Theatre
 Clear Springs Animal Hospital
 Development Engineering Services
 Employees of Wilson-Mohr
 Half Price Books
 Incredible Pizza
 Paradise Coffee
 Putt-Putt Fun House
 Seabrook House of Flowers
 Templin Photography
 Tommy's Seafood Steakhouse

Anne Bernay, Blanka Brhlik, Donna Cox, Alicia Dague, Joanie Garro, Beth Haas, Karen Hall, Cristen Reat, Elizabeth Stevens, Charlyca Wheeler

We are so grateful for their donations and/or hard work!

A special thanks to the ownership and employees of D'Vine Wine-Kemah for the time and effort put forth in support of our event.

Greater Clear Lake Families Exploring Down Syndrome

Phone (832) 457-2775

E-mail gclfeds@clearlakeds.org

Website www.clearlakeds.org



About Our Organization

GCLFEDS provides support and resources to individuals with Down syndrome and their families. Our family support programs educate and empower families to ensure the success of their children in the larger community. Monthly meetings, socials, new parent support, a lending library and annual conference are a few of our activities.

GCLFEDS promotes awareness, understanding and inclusion in our communities. Through presentations and

the DVD entitled "Living with Down Syndrome: Turning Fear Into Hope" we help medical professionals and hospitals provide a more positive outlook to new parents. We are working with local school districts and colleges to ensure the best education for our children.

GCLFEDS focuses on ensuring a positive community outlook and ample opportunity for individuals with DS to succeed. We believe in our kids and know that they can do great things! Won't you join us?

The Greater Clear Lake Families Exploring Down Syndrome newsletter is published every other month and is a benefit of membership in GCLFEDS. Copyright © 2008 – All Rights Reserved.