

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.

October

22 DS Awareness Month & Explorer Awards

November

19 NDSC Conference 2009 Recap Beth Haas

December

No Meeting

Events:

October

17 Teaching Tools for Students with Intellectual Disabilities Susan Peoples
 All Day Seminar
 Life Church

December

12 Christmas Social 3-6 pm
 Life Church

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Legislative Advocacy – What We Can Do! By MG Spanial

Recently The ARC of Texas contacted GCLFEDS about our willingness to host a brief session on Legislative Advocacy. On August 27, members of GCLFEDS met at a local Mexican restaurant to hear Dawn Choate of The ARC's Governmental Affairs Team. She provided background information on the most recent State Legislative session and recommended ways we can get more involved in getting the word to our legislators.

Miss Choate began by reviewing the 2009 legislative session. Senate and House bills pertaining to state schools, Medicaid buy-in, education and employment were addressed in the last legislative session or, in some cases, will need to be brought forward in the next session. Just a few items of note from this legislative session by category were:

- State Schools
 - § SB 643 is the conditions bill which was declared an emergency item by the Governor in January 2009 and increases oversight in our Texas institutions and community placements for people with intellectual and developmental disabilities.
- Medicaid Buy-In
 - § SB 187 was signed into law on May 13, 2009 and requires the Executive Commissioner of the Health and Human Services Commission to develop and implement a Medicaid buy-in program for children with significant healthcare needs.
- Education
 - § SB 451 was passed by the Senate and house and provides training for regular education teachers who



Texas State Capital

teach students with disabilities.

- § SB 100 develops professional development institutes for teachers and paraprofessionals who teach students with disabilities and includes a pilot Applied Behavior Analysis coached/mentored training option.

The ARC's Governmental Affairs team works to educate legislators, train community groups like ours, and organize in supportive ways those who wish to make an impact on their community and state law. Dawn also mentioned that by calling 281-388-1165, you can inquire about the next IEP Training session. ARC trains folks to work as advocates when parents go to IEP meetings at school.

The key is to know when, why and how to communicate with our officials. Dawn reviewed the public policy processes; it became clear that for a bill that benefits our children with special needs to become law, the best time to contact officials is between sessions. There are 35 House and 18 Senate Standing committees. Committees to target about special needs legislation are Appropriations (the money), Health & Human Services, and Public Education.

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Melissa Collins' daughter,
Emma

A Word from the Board by Melissa Collins

I am so grateful to be a member of GCLFEDS. I have been serving as the treasurer since January of this year and it has been a wonderful experience. My husband Keith joined my little family of three including Kayla (18) and Jonathon (15) in April of 2004. Since then we have grown to a family of seven adding James (3), Emma (2), and Michael (2 months).

When we were expecting Emma, the results from a triple screen came back as positive for Down syndrome. We did not want to have an amniocentesis, so we were not sure she had DS until she was born. I read books and did a good bit of research after the results from the blood test, but the time immediately following her birth was still difficult. That is when our pediatrician gave us contact information for Ellen Lachney, who was then a member of the board. GCLFEDS has been a great support for our family since Emma was only a few weeks old.

I am excited about our annual Explorer Awards, which will be presented on October 22nd, recognizing those in our communities

who support and accept individuals with DS.

Another fabulous opportunity in October is to hear nationally-renowned speaker and educator Susan Peoples speak on *Teaching Tools for Students with Intellectual Disabilities*. A mother of an accomplished sixteen-year old son with DS, Susan has 30 years of experience in educating individuals with ID. We are so fortunate to be able to bring her to Houston – this is a speaker not to miss!

As treasurer, I have come to learn much more about what it takes to keep our group going and my appreciation has grown immensely. I hope that each of you will consider serving on our board or finding other ways to help support GCLFEDS. If you would like to volunteer go to our website at <http://www.clearlakedes.org/> and click on the Volunteers tab. From there you can fill out the Volunteer Interest Form so that we can find out where your interests and talents lie. I look forward to working with you!

Board of Directors & Committees

If you are interested in helping on the Board or a committee, please contact us at gclfedes@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		
Secretary	Alicia Dague	sec@clearlakedes.org	832-275-9365
Treasurer	Melissa Collins	treasurer@clearlakedes.org	
Director	Denise Chapman	director@clearlakedes.org	281-283-3561
Director	Joanie Garro	education@clearlakedes.org	832-483-1869
Committees			
Outreach	Beth Haas	outreach@clearlakedes.org	832-689-5961
Outreach	Elizabeth Stevens	outreach@clearlakedes.org	
New Parent	Cristen Reat	newparent@clearlakedes.org	713-417-9398
Public Relations	Lilliana Monita	pr@clearlakedes.org	
Newsletter	Anne Bernay	newsletter@clearlakedes.org	832-457-2775
Fundraising	Open		
Social	Open		
Librarian	Maria Castillo	library@clearlakedes.org	
Webmaster	Joel Burdeaux	joelburdeaux@gmail.com	

Register Now to Hear National Speaker Susan Peoples

Special Offspring



Greater Clear Lake
Families Exploring
Down Syndrome

BRING YOU

"Teaching Tools for Students with Intellectual Disabilities"



The first initiative in providing curriculum resources designed to meet the specific learning needs of children who have Down syndrome and other developmental delays.

Saturday, October 17, 2009
8:00 a.m. - 4:00 p.m.
Life Church
9901 Windmill Lakes Road
Houston, TX 77075

REGISTRATION:

Registration (closes 10/14/09)
\$50.00 per person
\$75 per couple (one participant packet)
\$6 for box lunch from Lenny's
(includes sub, chips, cookie, soda or water)
(please specify turkey, club, veggie or roast beef)

NO CHILDCARE AVAILABLE!

**IACET CEU Certification Available
(additional \$20.00)**

CEU Certification is through Grace College, Winona Lake, Indiana, an Authorized Provider for granting CEU credits that meet the standards and criteria of the International Association for Continuing Education and Training (IACET).

REGISTER ONLINE AT WWW.CLEARLAKEDS.ORG

Welcome Members!

Thank you for supporting GCLFEDS.

Blaire Alise Donnelly

Bryan & Jody Koch – Blake Allen (2)

Ted & Annie Williams – James Braylon (1 month)

Thank You Renewing Members

Patty & Omar Cortez – Crystal (5)



Blake (2)

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 receive discounts on various events throughout the year.

Meet Our Member: Blake Allen Koch by Jody Koch

"Your baby has Down Syndrome"

When I went into the hospital the morning of April 2, 2007, I didn't know what to expect. Time flew by as they prepped me for surgery. I couldn't wait to see my baby boy. I had this weird feeling that he had Down syndrome, but everyone thought I was just crazy and paranoid.

When the c-section started, I looked at my husband and said, "Just look at Blake's eyes. If his eyes are slanted up and puffy looking, he has Downs." Bryan had no idea what to look for, but he knew the moment he laid eyes on Blake that he did have DS. I didn't hear Blake crying when they pulled him out. I panicked and said, "Why don't I hear him crying?" After a few minutes, I heard a weak cry. I knew something wasn't right. They kept having to revive him, and then they finally brought him to me for just a minute. I was terrified! I didn't know what to do or what to think. About an hour after they brought me back to the room, the doctor walked in with no baby. I frantically asked where Blake was. He told me that Blake had to be on oxygen because he couldn't breathe on his own. They also told me that they THOUGHT he might have Down syndrome. I burst into tears. I still hadn't seen him for more than a second. I wanted to see him and kiss him and hold him but I couldn't because he was in an oxygen tent.

The next morning at 5:30am the nurse wheeled me into the NICU to see my son and let me touch him for the first time. I was nervous. The moment I saw him I couldn't control the crying. This was my baby and-Down syndrome or not - he is PERFECT! What is "normal" anyway? This was the perfect baby and he would have a wonderful life.

I was released from the hospital after 4 days, but



Blake had to stay until he could breathe on his own and drink more formula. It was so difficult to leave the hospital without my baby. I was so sad and depressed. Seven days later the doctor said Blake was strong enough to go home. I was so excited to finally bring my baby home.

The first several months were a blur. Being a frantic, sleep-deprived first-time mom, I can't remember much of it. I just remember talking to a woman who had a son with DS herself. She talked for 45 minutes about all the things that went wrong with her son. I listened in fear and sobbed for hours after I hung up. This woman told me that Blake would probably not walk until he was 3-4 years old; he would most likely projectile vomit; he would need open heart surgery and on and on. How could I manage? I didn't know if I could.

Open Heart Surgery

It came time to take Blake in for his first heart echo. We were really nervous but excited to find out if Blake had the typical DS heart defect, AV Canal Defect. Whew! The doctor told us that Blake DID NOT

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Meet Our Member, cont.

Continued from page 4
have an AV Canal Defect. They said he just had a small hole in the top and a small hole in the bottom of his heart. They said that the holes could possibly close on their own during the first 2 years of his life. Now we just had to wait it out. We ended up going for an echo once a month. For the first 7 months, the results were always the same: "The holes might close on their own." But during the visit when Blake was 8 months old the doctor noticed something wasn't right.

We took Blake to Texas Children's Hospital for a second opinion. It was then that our world came tumbling down. Blake did, in fact, have the AV Canal Defect and would need open heart surgery immediately. The surgery was scheduled for January 30, 2008. In the meantime, we had to pull Blake out of daycare so he didn't get sick. Nana, Bryan and I took turns watching him during the week. We were successful; he didn't get sick. When we went in for the surgery, it was terrifying. My little man would go through a terrible ordeal. I prayed that he would pull through it.

When they checked Blake into the hospital, they took his urine, blood, temperature and weight. Was he healthy enough to undergo surgery? YES! They hooked Blake up to an IV. Blake screamed bloody murder. We then realized this would be a LONG stay at the hospital. We had to constantly monitor Blake to make sure he didn't pull out the IV. How the heck do you keep a 10-month old from pulling on something that is foreign to him? Plus, I had terrible morning sickness and was exhausted since I was 11 weeks pregnant with my daughter.

After the LONG night went by, it was now time for Blake's heart surgery to take place. We waited in the room for the nurses to come and get us. Tick, tock, tick, tock. It felt like forever. Then we found out that there was a kiddo who was life-flighted in during the night and they had to bump Blake for a

month. We couldn't believe that we would have to pack up and try this all over again a month later.

February 24th finally came around. It was time for Blake to get poked and prodded again to find out if he was healthy enough to go through surgery, which he was! The IV was placed. This time it was better because we knew what to expect. Poor Blake. He didn't like it one bit, but he was a trooper as usual. The night took forever to go by. Finally the morning came. Blake wouldn't be going into surgery until noon. The hours felt like days. They came to get us. This time it was really happening.

As they took us in the elevator to the surgical floor, my heart pounded as I held Blake close to me. I was so scared. They brought us in to the "pre-op" area, where I began to cry. I held him tight as he smiled and flirted with the nurse like nothing was going on. This broke my heart. I asked them to give him something because he had really bad stranger anxiety and they gave him what they called a "kiddy cocktail" to relax him. Within minutes they took him from me and he was like Jell-O: no smiles, nothing. It broke my heart to see him looking over the nurse's shoulder with no expression on his face. Blake has NEVER had a blank look on his face.

We headed to the waiting area. We got a status report every hour. After just 6 hours, the doctor came down and said he pulled through it great and that he would be moving Blake to the ICU for recovery. I was so relieved: the hardest part was over. Now it was time to face him with all the tubes and stuff coming out of him. I tried my best to prepare myself, but was still uneasy to see my baby like this.

As I walked around the corner of the ICU room where Blake was, my heart dropped. I cried uncontrollably



seeing Blake the way he was. I couldn't stop crying. The doctor told us to go home and get some rest, that he was in good hands and we would need to be well rested to take care of him during his recovery. I hated to leave my baby. I had never been away from him overnight. So it was tough to walk out the doors, but we did.

That next morning they said that Blake was starting to wake up. I rushed up there to be by his side, only to find out I upset him more than made him better. As soon as Blake heard my voice, he began thrashing around, crying and screaming, but you couldn't hear him because the ventilator tube was still down his throat. His eyes looked so sad. The nurses told me to leave right away because I was upsetting him. Blake wanted me to "save" him, but I couldn't. I couldn't comfort him or anything. If Blake got too upset, he might damage his throat from the ventilator tube. They had to strongly sedate Blake to get him to calm back down.

The next morning rolled around, again. We got good news today.

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GCLFEDS is pleased to announce that we have been added to the approved list of organizations that participate in the Combined Federal Campaign (CFC).

What does this mean for GCLFEDS? Individuals that work for Federal Agencies (i.e., NASA, U.S. Post Office, SSA) are able to select charities of their choice and direct a portion of their paycheck to that particular charity. If you know anyone who works for a Federal Agency, please encourage them to consider making a donation to our organization. Our CFC number is 28017. A special thank you to Beth Haas for heading up GCLFEDS' CFC application effort!

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.
For more information
call (281) 736-8008 or
email [gclfeds@
clearlakeds.org](mailto:gclfeds@clearlakeds.org).

"More Alike Than Different" by Beth Haas

Last month I had the pleasure of attending the National Down Syndrome Congress's National Conference in Sacramento. If you have never been to a NDSC conference, I definitely recommend that you go. The variety of activities and speakers is impressive but my favorite part was seeing all the children and adults with Down syndrome. It was truly a beautiful sight.

This year's theme was, "More Alike than Different". By using examples from their own lives, the self-advocates really drove this point home during their motivational keynote addresses. Be sure to check out their inspiring stories on the NDSC website www.ndsccenter.org.

At our November meeting I plan to give an overview of the conference and pass along information that I found helpful. The workshops I attended are as

follows:

- "Supporting Positive Behavior Change" presented by Scott Shepard, M.A., Ed.
- "Supporting Higher Math: Songs, Stories, Games and More" presented by Linda Chan Papp, M.A.
- "Teaching Children with DS to Read" presented by Sue Buckley and Julie Hughes
- "What Your Other Children Without DS are Thinking: Sibling Issues" presented by Dr. Brian Skotko and Susan P Levine

If any of the workshops listed above are of particular interest to you please let me know and I can get you further information on that topic. Next year's conference is in Orlando and I am sure that it will be a wonderful event. However, you don't have to wait until next year to hear world-class presenters! Our Oct. 17 conference brings Susan Peoples, a nationally-renowned educator, right here to Houston.

Upcoming GCLFEDS Meetings

Thursday, October 22
Down Syndrome Awareness
Month

GCLFEDS will also present the 2nd Annual Explorer Awards, recognizing individuals and organizations within our community who support the GCLFEDS mission of awareness, understanding and inclusion for individuals with Down syndrome. Please come celebrate these amazing recipients. The 2010 Board of Directors will be elected as well.



Thursday, September 17
National Down Syndrome
Congress Conference Recap

Community Outreach Chair Beth Haas shares valuable information from the NDSC Conference sessions she attended – a meeting not to miss!

Legislative Advocacy, cont.

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Since legislators are frequently very busy during the 140-day session, it makes sense to contact local representatives during the "off" season.

To find out who represents you go to <http://www.legis.state.tx.us/> and look for the "who represents me" box. Then just enter your address and your representatives will appear.

Tell your story, or testify on interim charge hearings. Influence the development of a bill and possibly even appropriations with your story. If you are not sure what to say, Ms Choate recommended 5 simple steps:

- 1) Thank them; tell them your name & where you live
- 2) Tell them what issue you would like to discuss
- 3) Tell them why this issue is important to you and your family
- 4) Tell them what you would like the decision-maker to do (have solutions – be direct)
- 5) Thank them for their time – provide in writing if possible.

So what can you do to influence legislation that affects our children with special needs?

- Write your story;
- Get to know your legislators;
- Be informed;
- Join organizations (GCLFEDS counts);
- Join mailing/alert lists;
- Share information with

GCLFEDS and other organizations you belong to

Members of GCLFEDS can work together in many different ways to influence legislative outcomes. As a chapter we could host an informal chat about issues or start letter writing campaigns. We could host events for policymakers or honor a local legislator. Connecting with the media to get "the story" public is another way GCLFEDS can have an impact. Starting a Government Affairs Committee would be a great way to organize our efforts.

Finally, for effective advocacy we must:

Educate
Participate
Network
Evaluate

Then do it again. And again. And again!

If you are interested in helping start a Governmental Affairs Committee or organizing specific activities to influence legislation, please contact us at glcfeds@clearlaked.org.

Websites to Check Out

www.reecesrainbow.org – adoption service for children with Down syndrome

www.specialkidz.net – directory of local support groups, service providers and much more

www.ndss.org/stories - The National Down Syndrome Society (NDSS) and its Ambassadors are pleased to unveil a new public awareness campaign, My Great Story, to honor and celebrate the 400,000 Americans with Down syndrome.

Meet Our Member, cont.

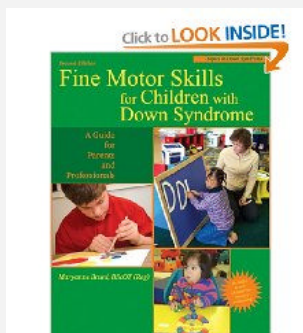
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Blake was breathing on his own and would be moving back to his own room in the afternoon. YIPPEE! We rushed up to the hospital and the minute I saw Blake, he gave me a grin. Even with all the pain, he mustered up a smile. What a fighter! We moved down to our own room at noon, and Blake recovered quickly and was released after just 5 days. Amazing!

We never looked back. He was a totally different kid. No more chronic cough. He had color in his skin. He just had more energy. What a miracle!

Having a child with DS has really been challenging, but very rewarding, too. Blake has been through two sets of ear tubes, heart surgery, a helmet for his flat head, several sinus infections, and more. That kid is the strongest person I have met in my life. Through all of this he still smiles nonstop. The smile is contagious. When I am down in the dumps, Blake comes over to me, wipes the tears from my face and smiles. He is the light of my life!

"The physical and medical characteristics of Down syndrome can interfere with our child's ability to take the next developmental step."



Fine Motor Skills in Children with Down Syndrome – A Guide for Parent and Professionals, written by Maryanne Brunni (Bethesda, MD: Woodbine House, 2006)

Available to check out from the GCLFEDS Library and from Amazon.com (\$13.57)

Book Review by Elizabeth Stevens

Fine Motor Skills in Children with Down Syndrome – A Guide for Parent and Professionals
By Maryanne Brunni

After months of effort and encouragement, your toddler is finally toddling all over the house. One of the most important gross motor skills – walking – has been achieved! After you experience the initial joy of seeing your little one explore the world in a whole new way, you may be wondering – what comes next? As my two-year old daughter, Claire, became more secure in her ability to walk, I started to realize that we now need to shift our focus to a new set of skills – the fine motor skills. "Fine motor" means the development of small muscle movement in the hands. It is the fine motor skills that allow us to find a penny in our pockets, button our shirts and write our names.

An wonderful book to provide insight and practical advice on helping your child reach these fine motor milestones is Fine Motor Skills in Children with Down Syndrome – A Guide for Parent and Professionals, written by Maryanne Brunni. Brunni was an occupational therapist for children with special needs for eight years prior to the birth of her daughter, Sarah, who has Down syndrome (DS). She thus combines the specialized training and experience of a therapist with the insight of a mother dealing with the day-to-day challenges and rewards of helping her child develop. She explains that our children can reach their developmental milestones, but benefit from help to move from one stage to another. "The physical and medical characteristics of Down syndrome can interfere with our child's ability to take the next developmental step." Thus, understanding the steps and helping our children move from one to the next is greatly beneficial.

Brunni begins the book by providing a model for understanding how fine motor skills develop,

which she likens to building a house. The foundation of the house consists of stability (a combination of strength and balance that allows us to push open a door), bilateral coordination (the efficient use of both hands to do an activity such as holding a bowl in one hand and stirring with the other), and sensation (knowing where our fingers, hands and arms are so that we can catch a ball or tie a ponytail). The next level is dexterity (the ability to make small, precise and accurate movements with our hands such as threading a needle) and the top level consists of daily living skills (dressing ourselves, using a spoon and fork, engaging in hobbies or sports).

Subsequent chapters explain how children with DS may differ from typical children in the development of fine motor skills and provide many practical examples of activities to help with each stage of development. For example, children with DS may have more trouble controlling their hands to grasp and release objects, making tasks such as stacking blocks more difficult. I have seen this in Claire's tendency to throw toys that she seems to want to play with. Brunni explains that the "throwing" phenomenon initially results from a child's inability to let go of things in a controlled way. However, without intervention, throwing can also become a habit. She suggests that parents encourage their children to "share" by handing toys to them in a controlled way. Once this is mastered, she suggests playing games involving dropping items into a container (particularly ones that make noise). The book takes us all the way from stacking blocks and pulling toys out of a bag, to getting dressed and learning to write. It is a good companion to occupational therapy and a wonderful source of information and ideas to help our children acquire their fine motor skills.

Community Events & Resources

Chronic Illness and Disability: Transition from Pediatric to Adult-Based Care

November 5 - 6, 2009

Denton A. Cooley Auditorium
Texas Heart Institute at St. Luke's Episcopal Hospital
6720 Bertner Avenue
Green Elevators, Floor B1
Houston, Texas 77030

presented by

Baylor College of Medicine, Department of Pediatrics, and
Texas Children's Hospital

The Maternal and Child Health Bureau- sponsored
Leadership Education in Adolescent Health (LEAH) Training Program

sponsored by

Baylor College of Medicine
Houston, Texas

To register/pay online visit the activity website at www.BaylorCME.org/CME/1424 and follow the instructions



Father's Joy 4th Annual Charity Golf Classic
Friday, October 23 at Wildcat Golf Club
12000 Almeda Road, Houston TX 77045

8:45 a.m. Shotgun Start

The Classic will benefit Father's Joy, a non-profit, Christian organization dedicated to supporting families and prospective families of children with disabilities. E-mail Kristin.tassin@fathersjoy.org for more information.

Save the Date

Practical Solutions for Educating Students with Down Syndrome

Guest Speaker will be

Bridget Murphy
from
Down Syndrome Guild of
Greater Kansas City

Saturday, January 16, 2010

9:00 AM — 12:00 PM

DSAH Resource Center
7015 W. Tidwell Bldg G Suite 108
Houston, TX 77092

ESTA CONFERENCIA SERA TRADUCIDA AL
ESPAÑOL - EN VIVO!



Volunteers Needed!

Join our 2010 Board of Directors!

Elections for 2010 officers and committee chairpeople will be held at our October GCLFEDS Monthly Meeting. If you have a passion for making a difference in the lives of people with Down syndrome and have time to commit to help our organization serve the community, contact Anne Bernay at 832-457-2775 or gclfeds@clearlaked.org

Board members must be able to attend Board meetings every other month, support events and activities by attending when they can and be willing to commit the time and effort required to carry out their specific role. For details about roles and responsibilities, please contact us.

Current open positions include:

- Fundraising Chair
- Social Chair
- Adult Programs
- Public Relations
- Librarian
- Newsletter Editor



Emma preparing for college!

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

The deadline for submissions to the Dec. newsletter is Nov. 15.

Greater Clear Lake Families Exploring Down Syndrome

Phone
(281) 736-8008

E-mail
gclfeds@clearlakeds.org

Web site
www.clearlakeds.org



A Little Inspiration

It is the start of another school year. We all have hopes and fears concerning the education of our children. Apart from the daily challenges of learning and inclusion, many of us may wonder "How far can my child go?" A world of opportunities is opening up for young people with Down syndrome and other developmental disabilities to go to college. In 2005, the Chicago Tribune did an article about the rise of such programs. See <http://bellevuecollege.edu/new/coverage/ChicagoTribune.pdf>. For the story of one self-advocate's

recent success in a program offered by the Columbus State Community College in Ohio see the Down Syndrome Association of Central Ohio's website at www.dsaco.net/node/306. And for a truly eye-opening experience, visit the Think College site at www.thinkcollege.net. It is a website devoted to the post-secondary educational opportunities for people with intellectual and developmental disabilities put together by the Institute for Community Inclusion at the University of Massachusetts Boston. As a new school year starts, let's all dream big!

Thank You!

Our gratitude and thanks to the following generous donors:

Teaching Tools Seminar Sponsors:
Virginia Metcalfe, Gary Greene Prudential Real Estate
The Reat Family

Our volunteers make all of our programs possible. Special thanks to:

- MG Spanial, Jody Koch, Elizabeth Stevens, Joanie Garro, Melissa Collins, Beth Haas, and Anne Bernay- writing for our newsletter this month
- Bill Stevens – organizing our 1st Dad's Night Out

- Beth Haas & Elizabeth Stevens – mailing information packets to ob/gyns in our area
- Beth Haas – getting GCLFEDS approved as a charity for the Consolidated Federal Campaign and representing us at the CFC Fair!
- Anne Bernay – speaking to Pasadena Social Security Administration employees for CFC Campaign
- Anne Bernay & Alicia Dague - organizing the Sept. & Oct. Sign Language Workshops
- Beth Haas & MG Spanial- setting up the Legislative Workshop in August

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.