

GREATER CLEAR LAKE Families Exploring Down Syndrome

Calendar of Events

Special Summer Monthly Meetings on Saturday July 24th and August 21st:

Join us at Clear Lake Baptist Church on Saturday mornings in July and August for the GCLFEDS monthly meetings. They will follow the Sign Language Workshop.
 9:00 am – Workshop
 10:00 am – Refreshments
 10:15 am – Speaker

Located at 15700 Space Center Blvd., (El Dorado and Space Center Blvd.)

July

- 14 Playgroup, Fun Max Jump-In on F.M. 528, 11 am to 2 pm
- 22 Mom’s Morning Out La Madeleine on West Bay Area Blvd., 9:00 am
- 24 Sign Language Workshop and Monthly Meeting Clear Lake Baptist Church, 9:00 am Workshop, 10:15 Speaker

Contents

| | |
|-------------------------------------|----|
| Do Your Homework | 1 |
| A Word from the Board | 2 |
| Board & Committees | 2 |
| 3 rd Annual Golf Tourney | 3 |
| Member News | 5 |
| Meet Our Member | 5 |
| Fundraising | 7 |
| Events | 7 |
| Do Your Homework, cont. | 8 |
| Book Review | 11 |
| Thank You | 12 |
| About GCLFEDS | 12 |

Do Your Homework – Preparing for the Transition to Kindergarten and Beyond

By Elizabeth Stevens

For any parent, sending a child to kindergarten is a big milestone that brings both excitement and a certain amount of trepidation. For parents of children with Down syndrome, the process can be both more complicated and more anxiety producing than for parents of a typical child. “Start early and don’t anguish” advises Cristen Reat, GCLFEDS member and mother of two boys, Martin and his younger brother, Vincent, who has DS. Cristen’s younger son will graduate from The Rise School of Houston and move on to kindergarten in August, and Cristen has done a lot of leg work to find the right place for him to start the new chapter in his school adventure. The experiences of parents who have navigated the system and explored their choices, including Cristen, Anne Bernay, and Lori Ferazzi, provide valuable insight into how we can better prepare to send our children to school.

Cristen took her own advice and started the process early. Although Vincent was attending Rise when he turned three, she went through the process of signing him up and having him evaluated for PPCD (Preschool Program for Children with Disabilities) in the public school. Even if you are not planning on enrolling your child in the PPCD program at three, going through the process can be useful. It makes your school district aware of your child, gets him or her into the system, and gives you an opportunity for a first glimpse at the school district’s approach to special needs children. However, the PPCD program may not necessarily be at your “home school” – the school that your child would be



assigned for kindergarten. Many school districts do not have PPCD or a preschool program at each child’s home school, but consolidate children from several schools in one location. Thus, more research will likely be necessary when preparing for the transition to kindergarten.

For Cristen and her husband Daniel, this process began about two years before Vincent would be ready for kindergarten. Cristen visited Vincent’s home school in the Houston Independent School District (HISD). In fact, she visited four times. Unfortunately, what she found was that special needs children at her home school were not included with typical children in any meaningful way. And although her older son Martin was at a magnet school in HISD that Cristen liked, she felt that school was lacking in resources for special needs children, and so her search continued. Cristen found that private school options were very limited in Houston and that choosing a private school devoted to special education could mean losing the opportunity for a more inclusive environment.

 continued, p. 8

A Word from the Board by Laura Johnson



I have had the privilege of serving as the GCLFEDS librarian for the past six months. Although my family and I have been members of GCLFEDS since shortly after the birth of my son Morgan, now age three, this is the first time that I have taken the chance to become more involved in this group. I have enjoyed participating more fully in GCLFEDS and would like to take this opportunity to share some of the benefits that the library offers for our members.

The GCLFEDS library contains books, pamphlets and videos on a wide range of topics relating to the special needs of individuals with Down syndrome and their families. A complete listing of the available resources can be found under the "Resources" link on the website. Books can be requested via the online Resource Request Form or in-person at monthly meetings.

In addition to the lending library, we are also excited to be launching a Book Donation Program in 2010. Many of our school and public libraries are sadly lacking in resources related to Down syndrome. Members will now have the

opportunity to donate books to the library of their choice in honor of a family member or loved one with Down syndrome. Request forms will be available at monthly meetings, on the GCLFEDS website, or from the librarian at library@clearlaked.org. GCLFEDS will make a \$5.00 donation toward the purchase of each book and will provide a book plate with the name of the honored individual. Books will be presented to the selected library during a storytime or other designated time, by the member family or a representative of GCLFEDS.

Another new opportunity coming to member families in the coming months is the Down Syndrome Affiliates in Action Book Bundle Program. GCLFEDS members will have the opportunity to purchase a set of five books about Down syndrome from Woodbine House publishers at a greatly reduced rate. The retail price for these books is over \$100, but our members will be able to purchase them at a 42% discount. Please watch your e-mail for additional details to come! The offer is for a limited time only and will require a minimum number of orders for our organization to participate.

Board of Directors & Committees

Board of Directors

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

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

GCLFEDS 3rd Annual GOLF TOURNAMENT A BIG SUCCESS!

By Anne Bernay

The 3rd Annual GCLFEDS Charity Golf Classic on May 21 at Southwyck Golf Club in Pearland raised \$10,000 to support GCLFEDS education programs and support for individuals with Down syndrome! MG Spanial, a member of the golf tournament committee and father of two children with Down syndrome, welcomed the golfers and expressed appreciation for their generous support of GCLFEDS. The links-style course provided an interesting and beautiful setting for the fun and competition, with twelve teams teeing off at 8 a.m. The golfers competed in a scramble format, with plentiful refreshments, a trivia

game and several other contests to liven things up. Play was followed with a BBQ lunch, a raffle and awards. Golf committee member Vince Johnson, father of Morgan, announced the contest and raffle winners and thanked the many sponsors.

The team of Woodcock, Hendrikse, Walters and Oloman took top honors with the best gross team score of 62. Haas, Guillot, Garrett and Durkin posted a 57.7 to win the best team net prize. Both teams earned elegant glass trophies and Golfsmith gift cards.

Individual honors went to Mike Guillot for closest-to-the-pin and Scott Dodge

for the longest drive. Both were awarded certificates for rounds of golf courtesy of Southwyck Golf Club.

In its first year, the raffle awarded prizes to ten lucky winners and raised a substantial amount of money. Raffle winners included: Tyler Fuhrken, Patty Cortez, Linda Nickerson, Robert O'Neal, Nancy H., Kerry Stein, Karen Phillips, Dorothy Cathcart, Pat Dague and Nancy Teichelman.

Tournament Chair Anne Bernay is especially grateful to the hard-working and dedicated Golf Committee of Steve Bernay, John

Haas, Vince Johnson, MG Spanial, and Ben Woodcock – without these guys the tournament would not have been possible! Many others assisted by obtaining sponsors, food and beverage donations, raffle prizes, and working at the event, including: Sasha Camacho, Alicia Dague, Pat Dague, Gina & Regina Gonzales, Beth Haas, Lisa Hartman, Dick Sauer, Nancy Spanial, Bill Stevens, and Ted & Annie Williams.

View pictures of the event, courtesy of Kari Noser Photography, at http://www.karinoserphotography.com/Galleries/GCLFEDS_GolfClassic2010/.

Thank you to our Tournament Sponsors:

Greater Clear Lake Families Exploring Down Syndrome

3rd Annual Charity Golf Classic

May 21, 2010
Southwyck Golf Course, Pearland TX

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THANK YOU, continued . . .

...and More Tournament Sponsors!

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The Bernay Family

Welcome Members!

Thank you for supporting GCLFEDS.
 Amy Coykendall & Justin Marshall – Zoe Navaeh (1 month)
 Karen & Trey Hall – Rowen (7)
 Irene Horn - Jackson (2 months)

Thank You Renewing Members
 Beth & John Haas – Annalee (5)
 Marlei & Doug Ebert – Amara (4)
 Nancy & M.G. Spanial – Marty (17), Beverly (14)

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: Daniel van de Rhee by Slyvie van de Rhee

Happy as always, Daniël steps out of the car; another day of school has begun. He smiles at his aide who helps him into the school and just before I close the door of the car, I hear a boy saying: "Hi, Daniel, good morning. Do you want to come with me to Mrs. Duncan's class?" When I drive back home, I feel thankful: Daniël found his place in life.

Daniël is almost six and attends kindergarten at Brookwood Elementary. He loves going to school and I am pretty sure he gives a lot of smiles everyday.

He does well at school, although he still needs a lot of help with his life skills like going to the bathroom and behaving in a socially acceptable way (not everybody likes to be hugged). Therefore, he spends a part of the day in an Alternative Academics class. The other part of the day he is with his peers in a regular class, without an aide. "I don't need an aide. When she is there, Daniel will focus on her instead of me," decided his kindergarten teacher, Mrs. Duncan, months ago.



Daniël was born on June 30, 2004 in Delft, in the Netherlands. We didn't know about his Down syndrome – we were expecting a healthy baby. The first year was hard: it took Daniël forever to learn to drink from a bottle, he was hospitalized three times, he never learned to crawl no matter how hard we tried. Our life looked like it had exploded and it took that whole first year to get the pieces together again.

----- continued, p. 6

Meet Our Member, cont.

When Daniel was two years old we moved to the US, to Fairfax, Virginia outside Washington DC. The first thing we learned about the States was the integrated education system. We were so surprised that Daniel was welcome at the same school where his big brother, Julian, started kindergarten. Daniel joined the special needs preschool program. In August 2009, we moved from D.C. to Clear Lake and enrolled both boys at Brookwood. The American open, friendly culture and the integrated school system helped us to learn to enjoy our life with Daniel and to feel like a normal family, with some extras.

In December 2006, in Fairfax, Daniel's little brother Simeon was born. This last year they were like twins, but now Simeon is catching up and developing faster. Which is

fine as long as Daniel is developing on a steady path. He is always proud to show the new things he learned like counting to ten and reading a bit.

Daniel loves music and loves to dance, but his most important task in life is to make sure everybody is always happy.



SPRING SOCIAL

The GCLFDS Spring Social was held on May 1, 2010 at Challenger Park. There were many fun activities for the kids, including a jumper, face painting, and a wonderful clown. Parents enjoyed hot dogs and hamburgers and good conversation. Thanks to everyone who attended and helped make it a fun and successful event.



GCLFEDS MEMBERS AND FRIENDS ENJOY A DAY OF GOLF AT SOUTHWYCK



Join GCLFEDS to Step Up for Down Syndrome

GCLFEDS is pleased to announce that we will be hosting a Step Up for Down Syndrome fundraising walk, October 16, 2010. This will be a fun-filled family event and we encourage you to get your family, friends and community involved.



Volunteers needed!

Special Summer Monthly Meetings on Saturday July 24th and August 21st:

Join us on Saturday mornings in July and August for the GCLFEDS monthly meetings. They will follow the Sign Language Workshops
9:00 am – Workshop
10:00 am – Refreshments
10:15 am – Speaker

Located at 15700 Space Center Blvd., (El Dorado and Space Center Blvd.)

For more information call (281) 736-8008 or email gclfeds@clearlaked.org

Step Up For Down Syndrome Walk



The Step Up for Down Syndrome Walk provides the entire community with the opportunity to celebrate individuals with Down syndrome and their families. The event promotes the acceptance of all people with Down syndrome. There are over 280 Down syndrome walks held worldwide. Greater Clear Lake Families Exploring Down Syndrome will host its 1st annual Step Up For Down Syndrome Walk on October 16, 2010 at Big League Dreams Sports Park in League

City. Our goal for this year is to raise \$15,000 and have 500 walkers – WE CAN DO IT!

Forming a walk team is the perfect way to honor your loved one with Down syndrome. A walk team can consist of your immediate family or 200 of your closest friends, family and neighbors joining to celebrate someone with Down syndrome. Most teams choose a name which honors their loved one with Down syndrome. Team registration is free for GCLFEDS members and \$25 for nonmembers. Each person participating will pay \$15 (age 13 and up) or \$5 (age 12 and under) and sign a waiver of liability form.

Registration for the walk is now available online at www.clearlaked.org.

Upcoming GCLFEDS Meetings and Events

JULY 24th - MONTHLY MEETING:
Creating a PATH for your child.

Join GCLFEDS for a presentation on Microboards. You, your family, and friends can create a nonprofit organization devoted to supporting your special needs child. Hear about this innovative way to support your child's dreams and plans for the future from Heather Burdeaux, the Regional Coordinator for the Microboard Collaboration with the ARC of Texas.

Moms & Kids Events in July

Playdate – Jump for Joy at Fun Max Jump-In, July 14th from 11am to 2 pm- 3100 FM 528, Suite A, Webster 77598

Moms Morning Out – July 22nd at La Madeleine, 929 West Bay Area Blvd, Webster 77598, 9:00 am

Sign Language Workshops

July 24th, August 7th and August 21st
9:00 am, Clear Lake Baptist Church

Do Your Homework, cont. from p. 1

Ultimately, Cristen found an alternative to her home school within the public school system – a charter school.

The enabling legislation to allow for charter schools in Texas was passed in 1995. According to the Texas Education Code, the purposes of charter schools are to (1) improve student learning; (2) increase the choice of learning opportunities within the public school system; (3) create professional opportunities that will attract new teachers to the public school system; (4) establish a new form of accountability for public schools; and (5) encourage different and innovative learning methods. For parents of children with special needs, charter schools can provide a smaller and more personal environment than many public schools and may have a more flexible and innovative approach to teaching methods.

Charter schools in Texas are primarily open enrollment schools -- meaning that they are not linked to the boundaries of a particular school district so that anyone within the school's geographic boundaries is eligible to attend. Charter schools are prohibited by federal law from discriminating on the basis of a student's disability. However, charter schools may face certain challenges in terms of access to resources to provide the full range of services for a special needs child. Although Vincent has not yet started kindergarten, Cristen has worked with the

charter school she selected to insure that therapists, para-professionals and other necessary service providers will be available in the charter school setting.

While Cristen's public school options were not what she wanted for Vincent, other parents have had found that their local public school is the right choice for their children. Anne Bernay's son, Peter, also attended Rise until age six. Like Cristen and her family, Anne and her husband, Steve, considered different options, including private and charter schools, but ultimately concluded that they wanted Peter to have the experience of attending school in his own neighborhood and with his older sister.

Anne also started the process early, setting up a meeting with the Clear Creek ISD elementary school which Peter would attend 18 months before he started kindergarten. That initial meeting was with the school counselor, vice principal and the diagnostician who would be coordinating his evaluation and IEP development. As Anne explains: "Steve and I shared our vision for Peter's future and discussed how we could all work together to give him the best possible education." The following spring, a group from the elementary school, including the regular education kindergarten teacher and the occupational and speech therapists, spent a half day at Rise observing Peter and learning about him. Once Peter started school, Anne found it somewhat difficult to adjust to



Spotlight on the Horizon School

Lori and Tom Ferazzi started the Horizon School in the fall of 2009 with the goal of providing a better academic experience for their son, Eric, and others with Down syndrome and similar developmental delays. They hope to build on the success of their first year in the years to come. As Lori explains, "We are proud of the curriculum we developed. Academically, we have seen a huge improvement in our students' reading levels, handwriting, verbal skills and understanding of their daily schedule. Socially, we have all grown and I think our community has benefited from seeing our children in a different light."

Although, initially, the program focused on students age 11-15, this year the school will be admitting students based on each individual child's abilities and level instead of focusing on an age group. Prospective students must meet preadmission criteria and spend time with staff and students prior to admission.

In addition to the academic curriculum, Horizon offers Speech and Occupational Therapy, as well as music class and Chapel. The school will also be continuing its fundraising efforts in the coming year.

----- For more information, see page 9



The Horizon School is
Accepting Applications for 2010 –
2011 School Year

The Horizon School is an academic-based school for students with Down syndrome and similar developmental delays located in Friendswood on the campus of Good Shepherd Episcopal Church. Our goal is to create an academic environment that is fun and rewarding for students, teachers and family members alike. Through individualized goals and personalized curriculums we will strive to instill in our students the love of learning and the pride of accomplishment so critical to their development. The students will learn the relevant skills needed to be productive members of society and build supportive relationships that will last a lifetime.

For more information about The Horizon School contact, Lori Ferazzi at 281-648-2466 or visit the website at www.thehorizonschooltx.com

Nondiscriminatory Policy
The Horizon School admits students of any race, color, national and ethnic origin to all the rights, privileges, programs, and activities generally accorded or made available to students at the school. The Horizon School does not discriminate on the basis of race, color, national and ethnic origin in administration of its educational policies, admission policies, scholarship programs, financial policies, and athletic and other school-administered programs.

Do Your Homework, cont.

having less contact with teachers than the daily interaction she had at Rise. But she took advantage of the opportunity to volunteer in the classroom once a week and maintained regular contact with his teacher, both with email and conferences, to stay involved in his classroom experience.

Peter's experience with the public school system has thus far been tremendously positive. Peter was fully included in his kindergarten class, and the whole school embraced the concept of inclusion for Peter. The federal Individuals with Disabilities Education Act requires that the states provide free and appropriate public education for individuals with a disability in the least restrictive environment. These terms may seem somewhat vague, and federal law does not contain the word "inclusion." However, the IDEA is, in fact, a powerful tool in defining what our public schools must do for children with special needs. The IDEA provides that the states must have in place procedures assuring that "to the maximum extent appropriate," children with disabilities "are educated with children who are not disabled, and that special classes, separate schooling or other removal of children with disabilities from the regular educational environment occurs only when the nature and severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" [20 U.S.C. Sec. 1412(5)(B)]. Anne has

found this to be the case with Peter's school. "Peter is treated as much as possible just like everyone else and as a result, he loves school, has made great friends in our neighborhood and is part of all of our school's activities. In addition, he is doing really well academically and the school staff is really responsive and proactive."

Anne knows, however, that not every parent of a child with Down syndrome in our area has had a positive public school experience. Some children with DS have been put into less inclusive settings and steered towards "life skills" subjects rather than the academic programs of their peers. Anne hopes that GCLFEDS can play a role in advocating in the school districts for greater resources for children with DS and in providing information on research-based best practices for teaching our children through conferences, workshops and other forums.

For parents who have not had a positive experience with their local public school, the private school options are limited. Private schools such as the Rise School can offer a wonderful environment for special needs children, but the Rise program ends in preschool, and for children entering kindergarten, there are not a tremendous number of such schools in the Houston area. For example, Lori Ferazzi, mother of Eric, struggled with the public school system after Eric graduated from Rise, and

Do Your Homework, cont.

was on the wait list for one of the few private schools in Houston, Briarwood, for over seven years. She and her family moved from one public school district to another in search of a better environment for her son, but still found the public school lacking in expertise. "While the administration and staff (at the new district) were certainly more accommodating, Eric was the only student with Down syndrome and we found ourselves constantly meeting with them to provide information and suggestions on working with him."

Lori's frustration with the public school system and the unavailability of spaces in private schools led her and her husband, Tom, to take the brave step in 2009 of starting their own private school for children with Down syndrome and similar developmental delays in Friendswood. "I didn't know how we were going to do it, but I knew there were other families out there that felt the same way we did. As a parent of a special needs child, you are constantly fighting the system and advocating for your child, which can be both mentally and physically exhausting. I think many families simply give up and take whatever they can get. We want to give those families a place where their children are safe, accepted and given the

opportunity to reach their full academic potential."

The Horizon School had a successful first year, with the students making wonderful progress. "It was an amazing first year and we saw dramatic changes in all of our students. One of our students was unable to write any letters and hardly ever talked, but over the course of the year we saw a huge transformation in both verbal and writing skills." Lori hopes to build on that success next year. (see Spotlight on the Horizon School, p. 8).

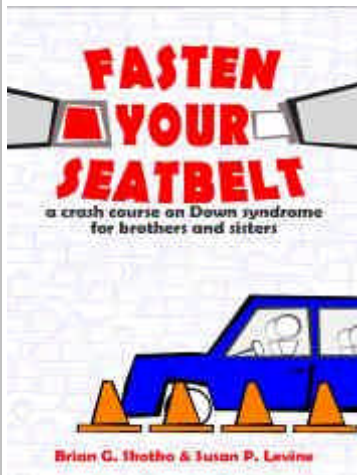
There is much we can learn from the experiences of Cristen, Anne, Lori and their families. Cristen's early research helped steer her away from educational environments she did not think were appropriate for her son, and led her to an alternative – the charter school – that not every parent might be aware of. For Anne, developing a relationship with the teachers, therapists and administrators in her school well before Peter entered kindergarten seems to have been the key to a successful transition. The lesson of her experience is that we should not be afraid to reach out to the school, and require that they prepare with us for the transition of our child into an inclusive public school setting. And Lori's unwillingness to accept a system that wasn't working for her son gave her the courage to create a school that will benefit not only her own child, but others who want a

specialized academic environment for their children. For Cristen, Anne, Lori, and their families, it seems that preparation and perseverance have been the keys to successful educational experiences for their children.

TIPS FOR PREPARING FOR SCHOOL:

1. Start early.
2. Research your home school by visiting more than once.
3. Explore alternatives including charter schools and private schools.
4. Get to know your school administrators and staff and work as a team to prepare for your child's entry into school.
5. Advocate for your child's right to an appropriate education and bright future.

Book Review by Cristen Reat



Dr. Brian Skotko is a physician at Children's Hospital Boston and has dedicated his professional energies toward children with cognitive and developmental disabilities. He is a national speaker, whose research has been featured in many journals and newspapers and in 2001 co-authored the book *Common Threads: Celebrating Life with Down Syndrome*. His sister with Down syndrome inspires much of his professional work. For more information visit www.brianskotko.com.

Susan Levine is a social worker and co-founder of Family Resource Associates, Inc., a nonprofit agency in New Jersey. She has conducted support programs for parents and siblings of children with differing abilities for the past 30 years.

Fasten Your Seatbelt: a crash course on Down syndrome for brothers and sisters

By Brian G. Skotko and Susan P. Levine
(2009, \$18.95 on www.woodbinehouse.com)

It is not breaking news that parents raising children with Down syndrome face many challenges, but what is it like to grow up with someone who has DS? How do brothers and sisters cope with having a sibling with DS in their lives? Parents who have the courage to ask their 'typical' children these questions often get surprising and abbreviated answers. Some teens may feel uncomfortable asking their parents questions such as Will my brother with Down syndrome get married? Sometimes I feel guilty that I can do things that my sister can't do. Is that normal?

Fasten Your Seatbelt is the first book of its kind written for teens and young adults who have a brother or sister with DS. Physician Brian Skotko and social worker Susan Levine teamed up on this project after having met over 3,000 siblings at workshops across the country. The result is this book, which is based on confidential questions and answers that the authors dealt with in the workshops. The target age group is 11-19, but young adults will also benefit from the thoughtful discussions in this book. The information is organized into 9 easy-to-read chapters featuring a question and answer format that addresses the most common concerns and emotions of teenage siblings.

The book has a conversational feel to it and can easily be used by parents to start a conversation with their typically developing children about feelings, worries and issues they have about their sibling with DS. It can also be used as a "how-to" guide for teens to read on their own. Some of the issues this book tackles include: facts about DS, how people with DS learn, handling parent and family conflicts, dealing with frustrating behaviors, managing uncomfortable situations, and what the future holds for people with DS.

The tone of the book is compassionate and honest. The authors delve into complex questions and validate feelings that siblings have, assuring them that these emotions are normal. It also provides useful suggestions, talking points and reasonable actions for the sibling to consider when confronting a particularly difficult issue, such as being embarrassed by a sibling's behavior, dealing with the "r" word or anger over perceived inequalities in housework.



We welcome articles and contributions to the newsletter. Send them to Elizabeth Stevens at gclfeds@clearlakedes.org.

Greater Clear Lake
Families Exploring
Down Syndrome

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(281) 736-8008

E-mail
gclfeds@clearlakedes.org

Web site
www.clearlakedes.org



Thank You!

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

- Anne Bernay – for her tireless work and wonderful success (together with the Golf Tournament Committee) in putting on a fabulous Golf Tournament!
- Tiffany Novick – for planning a fun-filled Spring Social at Challenger park, complete with a clown, jumper, face-painting and more!
- Alicia Dague and Nancy Spanial – for all their hard work thus far as chairs of the GCLFEDS Step Up for Down Syndrome Walk committee.
- Vince Johnson – for all his efforts on the Step Up Walk website, at clearlakedes.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.