

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.

February

19 Back & Neck
Health for
Individuals with
DS & Their
Caregivers Dr.
Michael Ennis

March

26 Parent Panel:
Education Lori
Ferazzi, Sean &
Bev McFerran,
Kristi Foret &
Jennifer Vincent

Events:

February

13 2nd Wine Tasting
Fundraiser
7 to 9 pm
D'Vine Wine
-Kemah
609 Bradford Ave.

March

12 Mom's Night Out
6:30 pm
Lupe Tortilla

Contents

My Valentine...	1
A Word from the Pres	2
Board & Committees	2
Member News	4
Meet Our Member	4
Santa is Special Guest	5
Fundraising/Events	6
Book Review	8
Community Events/Volunteers Needed	9
Inspiration & Thanks	10

My Valentine: What Our Children with Down Syndrome Have Taught Us About Love By Elizabeth Stevens

Some people call Valentine's Day a "greeting card holiday"-- designed to sell cards and flowers. While my husband might agree with this as he dutifully brings me a sentimental card and flowers every February 14th, Valentine's Day can also give us a chance to genuinely reflect on love and what it means to us. As a relatively new mother of a child with Down syndrome, much of the focus of my first 18 months with Claire has been on what we must teach her - crawling, walking, constructive play, and communication - with the assistance of a number of therapists, whose titles and functions I sometimes have difficulty keeping straight. But more important than what I have taught Claire in her first 18 months of life is what she has taught me about love and what it means to be a family.

My husband and I met and married relatively late in life, and so when we had our first child without difficulty or complications, we were pretty pleased with ourselves. Our son slept through the night at six weeks old, he didn't cry or fuss, never had so much as a cold, and was walking and talking up a storm by his first birthday. We wanted to follow up with a sibling for him as soon as possible, so that they would be close together in age, and our perfect family would be complete.

Claire came nearly two months early by emergency C-section, and I did not see her or hold her as she was rushed to the NICU. I did hear the murmurings of the doctors and nurses in the room that she might have Down syndrome, and I felt that my perfect plans for the perfect family were instantly shattered.



Claire Stevens, her mom's Valentine

Claire spent five weeks in the NICU with a number of medical issues, most of which resolved themselves before she was released from the hospital. But I brought her home with a feeding tube. It was months before she slept through the night. She had illnesses that sent us to the emergency room, and she took her time to roll over, babble, and finally smile.

As the months went by, and I began to know Claire as a person rather than a diagnosis, I learned that life is not about plans for a perfect future, but about the moments of perfection in each day. Although it took Claire almost eight months to start smiling, once she did it was well worth the wait. She has a smile that can light up a room. And while other people may sometimes have to work for a smile from her, Claire smiles at me with abandon. She has remarkable blue eyes. It is her beautiful eyes that people comment on when they first meet her, not Down syndrome. She loves to bounce and spin in her daddy's arms, just like her brother, until I ask them to stop because they are

Continued on page 3



A Word from the Pres by Anne Bernay

The Board of Directors and Committee Chairs met on January 25 for a half-day of planning and goal setting. Taking into consideration the results of our member survey, our current resources (both manpower and funds) and the many ideas for new programs and services, we came up with a plan for 2009 that we hope will address our members' needs!

Members clearly indicated on the survey that informational activities like monthly meetings, the annual conference and newsletter are very important to them. The types of information most desired fell into two main areas: education and medical. Socials likewise were considered important by a majority. The other area of high importance was outreach, both to new parents and community members such as educators, medical professionals and the public.

The plan for GCLFEDS for 2009 focuses more monthly meetings on education and medical topics and will continue the annual conference in the fall. In addition, we will increase the number of monthly meetings this year from 9 to 11. Additional social events will

increase the opportunity for interaction and information-sharing. We hope to revamp our new parent packages to include families of older children and grandparents as well as provide some of our materials in Spanish.

In the outreach area, we will focus this year on presenting to doctors and additional hospitals, while continuing our presentations to nurses, ECI and community groups. Our prenatal education program, in conjunction with Father's Joy, is moving forward and we hope to roll-out the new presentation in the fall with CME credit for medical professionals. A new program called "Including You" is being developed in collaboration with Father's Joy and will help promote inclusion at our local schools. 1-1 Early Interventions, provided by UHCL Early Childhood Clinic, will continue as will Film Club's social skills training for members.

I want to thank the Board and Committee Chairs for generously offering up their time and energy to make all of this possible this coming year. We'd love for you to join us!

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		
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	Tiffany Perez	newparent@clearlakedes.org	
Public Relations	Lilliana Monita	pr@clearlakedes.org	
Fundraising	Open		
Social	Open		
Librarian	Maria Castillo	library@clearlakedes.org	
Webmaster	Joel Burdeaux	joelburdeaux@gmail.com	

My Valentine: What Our Children Have Taught Us, cont.

Continued from page 1

making me dizzy. One of her current accomplishments and favorite things to do is clap. She will clap both little hands vigorously together for all important events like getting a new diaper or another spoonful of baby food. For her older brother, the game of "Claire's going to get you" is endlessly entertaining. She perks up whenever he is near and will make every effort to get handfuls of his blonde hair.

Parenting is always a challenge. There are tantrums, illnesses, and sleepless nights for all parents. But most of us find that the rewards outweigh the difficulties. One of the most surprising things about being a parent of a child with Down syndrome is the discovery that even though the challenges may be greater, the rewards are bountiful. We often focus on the practical needs of our special children – medical issues, therapy, and inclusion in school. But we should also take time out to

focus on what our children with Down syndrome have taught us about life – courage, strength, beauty, joy, affection and love – that we might have missed out on had they not come into our lives.



COURAGE & STRENGTH

Tracy Kachtick-Anders
- mother of Wyatt

My Valentine is Wyatt. He is five years old. He is why I am brave and strong, and why I learned to speak my mind and stand up for myself and others. Wyatt teaches me to slow the heck down, to accept people as they are, and to jump for joy at small accomplishments. I see him as a little ambassador to the non-Down syndrome world, showing the naysayers how much he and his "cousins" have to offer. Wyatt rocks!



BEAUTY

Anne Bernay -
mother of Peter

My six-year old son, Peter, is a real sweetheart. Often, right out of the blue, he will look me straight in the eyes and sign 'beautiful.' Invariably, my eyes well up and my heart swells with pride and amazement that this little boy thinks I'm beautiful. To me, he is the beautiful one – inside and out. His compassion for his friends, family and even strangers never ceases to amaze me. His ability to instantly forgive is truly something we should all emulate. And his sly sense of humor, often communicated without a word, is a joy to all of us who know him. I pray that I can learn well the lessons Peter is teaching me about love, for then I will truly be beautiful.



JOY

Beth Haas - mother of
Annalee

Valentine's Day has always been one of my favorite holidays. Great cards, yummy treats, and an occasional gift . . . but nothing can compare to Valentine's Day 2005. Annalee was born on February 8, 2005, and due to concerns for her health, the doctors had not allowed us to hold her. We were allowed to put our arms around her while she lay in her bed, but that was all. On February 14 we were finally allowed to hold our first born child. What a wonderful feeling that was. The memory still fills my heart with joy.



Continued on page 7

Welcome Members!

Welcome New Members

Gabby Lewis
Yazmin Ortega
Natalie Lanclos
Jerilee & Doug Boiley
Alicia Sanchez

Juan Raymundo
Javier Gembe
Minerva Ramos
Edith Montalvo

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

Denise Chapman
Joanie Garro & Ted Rickerl – in loving memory of Joey
Chris & Alicia Dague – Anna, age 4
Steve & Anne Bernay – Peter, age 6
Keith & Melissa Collins – Emma, age 1
Doug & Marlei Ebert – Amara, age 3
Kileen McDonald & Pam Colwell – Ches, age 1
Daniel & Cristen Reat – Vincent age 5



Meet Our Member: Annalee Haas by Beth Haas

This month I have the pleasure of introducing my daughter Annalee to all of you. She will turn four next month and is the oldest of three girls. She loves to laugh, dance, and play with her sisters. She works harder than anyone I know when she is trying to learn something new. Her favorite foods are apple sauce, yogurt and just about anything with ketchup on top. When I was thinking about what else to tell you about Annalee, I thought it would be fun to ask Annalee's family members to tell a favorite story about Annalee or something she does that makes them laugh. Here is what they had to say.

"Annalee – just saying her name evokes such images!! This beautiful little girl greeting us with open arms and a big smile, so excited to see us. Annalee – dancing and singing to the music which she loves. Annalee – surrounded by stacks of books, totally involved in their world. Annalee – loving, sweet, happy. She is one of the biggest, brightest spots in our lives. Without her, our world would be greatly diminished. We love and accept her just the way she is – just as she loves and accepts us the way we are." – Oma and Opa

Annalee's cousin Savannah said, "I thought it was funny when Annalee colored on the tables, walls, and couch with her red marker."

Annalee's "Mimi" wrote, "I am the grandmother



of twelve wonderful grandchildren. Annalee is the tenth and the wonder and miracle of her birth was as anticipated as my first granddaughter 26 years before. I'm not going to go into the medical problems that she brought with her as her parents would be better at that. I was in the waiting room at St. Luke's when she was born. It seemed like forever but finally my son came in. John was a first time father and had gone through months worrying about Annalee's expected heart condition. He looked relieved as he said she was beautiful and doing better than expected, and oh, it looks like she might have red hair and perhaps Down syndrome. We didn't know at that time how it would impact her life. There were challenges on feeding but from the very first her smile and beautiful blue eyes captured my heart. She may have been a little slower

Continued on page 5

Meet Our Member, cont.

Continued from page 4

crawling and then walking, but once she got the knack of it, she never slowed down again. I have attended many "pretend" tea parties, watched her perform in her ballet class and play dress up with her little sisters. She loves any books and even enjoys home decorating and Popular Mechanics magazines. She likes to climb and is adept at finding all sorts of things to get into. She is a happy little girl who brings happiness and joy to everyone around her. My very best Christmas memory this year was walking into church to meet the family on Christmas Eve. Annalee looked up and saw me and with the biggest smile in the world, said "Hi Mimi" as if I was Santa Claus. She has enriched our lives immeasurably."

Annalee's cousin Ceci said, "I like to watch Annalee make drip (sand) castles on the beach with

her Opa."

"When you ask Annalee to smile, for a photo or something like that, she scrunches her eyes closed and puts a big goofy grin on her face. That always makes me laugh." – Annalee's cousin Samantha

"It was the day after Annalee's heart surgery when we went in to see her. The poor little thing had wires and tubes attached to her everywhere but she lit up when we came in the room and gave us a huge smile. I remember thinking that if she can go through all that she just went through and be so happy, we could certainly bear our hardships with a smile." – John, aka Daddy

Annalee is like a little ray of sunshine in my life. I can't wait to watch her grow up. I feel so blessed to have a front row seat. I am sure she is going to put on quite a show.

Santa is Our Special Guest by Beth Haas

GCLFEDS had their second annual Christmas party on December 6 at Life Tabernacle Church. A good time was had by all in attendance.

Everyone brought a dish to share and the food was delicious. This year we were lucky to have two different Girl Scout troops volunteer their time and supplies to help us with the party. The girls helped our kids create one-of-a-kind picture frames as well as frost and decorate cookies. The kids

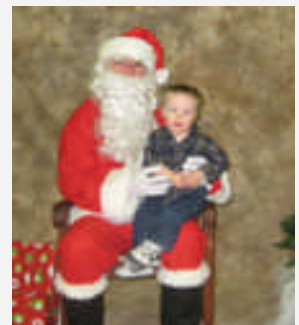
also had a great time playing with the assortment of toys brought by some of the members. There was a lot of giggling, running around, and a few games of basketball supervised by some very watchful daddies.

Once again, Santa made an appearance at our party. He stayed around long enough for the kids to get a personal picture with him that they were able to put in their new picture frames. Ho Ho Ho!

"Annalee is like a little ray of sunshine in my life."



Thanks to all who helped make our holiday party a success!



Cooper meets Santa

GCLFEDS Board asks Santa to be good to us in 2009!



Upcoming GCLFEDS Events

May Social
Saturday,
May 16
3 - 6 p.m.
Challenger
Park
Pavilion 3

GCLFEDS provides the main dish and drinks. Please bring a side dish or dessert to share.

Activities for the kids along with a play area.

RSVP to gclfeds@clearlakedes.org or (832) 457-2775

Wine Tasting Fundraiser
Friday, February 13 \$25 per person
7-9 p.m. \$40 per couple

D'Vine Wine~Kemah
Tickets available at the door

Please join us and support the programs of Greater Clear Lake Families Exploring Down Syndrome

Mom's Night Out
Thursday, March 12
6:30 p.m.
Lupe Tortilla, Bay Area Blvd.
RSVP to gclfeds@clearlakedes.org or Anne at (832) 457-2775

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

Thursday, February 19
Back Health

Dr. Michael Ennis, a chiropractor with over 15 years experience, will speak about back health for individuals with Down syndrome and their families.

Thursday, March 26
Parent Panel – Working
with Your School

Five parents of children with Down syndrome and autism share tips for

creating a good relationship with your child's school and answer your questions.

Thursday, April 16
Using ASL to Help Your
Child Communicate

Katie Tryon Raugh, a daily user of American Sign Language and ASL instructor, will teach some basic sign language and discuss how ASL can help children with Down syndrome communicate before they can talk as well as reinforce speech development.

My Valentine. Cont.

Continued from page 3



AFFECTION

Alicia Dague - mother of Anna

My kids have taught me that love truly can be unconditional... why hold a grudge when you could have a hug instead?

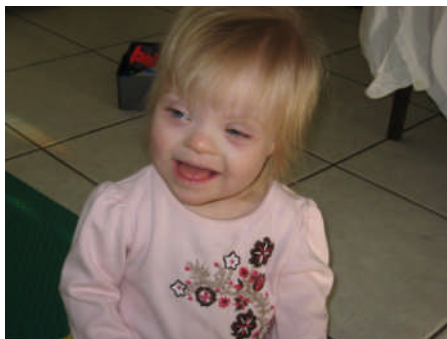


MORE AFFECTION

Keith and Melissa Collins - parents of Emma

Emma has given to us . . .

Endless
Meaningful
Moments of
Affection

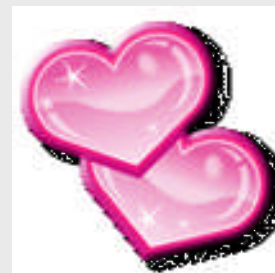


LOVE

Elizabeth Stevens - mother of Claire

Claire has shown me the joy in the little moments of each day with her. When she first came, I wondered why this had happened to us. Now I wonder at my luck to have Claire in my life and marvel at how much she has opened my heart. At my wedding, my husband's sister read the lyrics from a John Denver song, called "Perhaps Love." While the words were meaningful to me then, they mean more now that I have my Valentine, Claire: "If I should live forever, and all my dreams come true, my memories of love will be of you."

Happy Valentine's Day!



"Claire has shown me the joy in the little moments of each day..."

SAVE THE DATE

Clear Creek ISD
Connections – Speaker &
Organization Booths
Saturday, April 4, 2009
9 am to 12 pm
Sponsored by CCISD Special
Education Department

"Their parents were told to expect nothing. But Jason Kingsley and Mitchell Levitz were lucky, because their parents didn't listen." - Jane Pauley

Book Review by Neesha Hosein

Count Us In: Growing Up With Down Syndrome

By Jason Kingsley and Mitchell Levitz (Orlando, FL: Harcourt Brace & Company, 1994). \$11.20 on Amazon.com for 2007 edition

This book is a verbatim account about literally growing up with Down syndrome, written by two young men, Jason Kingsley and Mitchell Levitz, and their families.

Both men are in their thirties now and this book was their commemoration of successes and an attempt for the men and their families to share their experiences with the world. Their mothers, Emily Perl Kingsley and Barbara Gibbs Levitz, wanted to inspire others to reach for the stars and be reassured that a child with DS can do just about anything.

The book illustrates the misconceptions that existed even at the time of their births more than three decades ago. One example is when Jason's mother, Emily Kingsley, was told he would be stricken with disabilities and doctors suggested institutionalization.

Jason expressed his discontent at what the doctors suggested and praised the efforts of his parents by saying, "I have a disability called Down syndrome. My bad obstetrician said that I would never learn and send me into a institution and never see me again. No way Jose! Mom and Dad brought me home and

taught me things." (page 21)

The men discuss their grade school experiences, likes and dislikes, regrets and successes. Some hot topics covered were: school, fun, girls and sex, career goals, politics and world affairs. Their perspectives on the topics are quite remarkable and they each have in-depth opinions about who they would vote for, how they would handle war and ... women.

To Mitchell, independence means that "you have to think that things do not happen overnight. It takes time. In my case, I do think that I know what I want to do. It's difficult processing that. I do want to live fully independently, without anyone looking over me all the time." (page 155)

Both men have had a great number of achievements, such as winning awards, being interviewed on TV and gaining national recognition for their hard work.

By the end of the book, there are no doubts that a person with DS can live a normal, happy life and enjoy the same things as peers and family members. This is definitely a very inspiring piece of work.

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.

RESOURCE FAIR MARCH 26 AT MALL OF THE MAINLAND

Gulf Coast Transition Task Force invites you to participate in the 2009 Transition Fair on March 26. This event is for students with disabilities, as well as their parents and/or guardians. Parents and students can get information about services, options and opportunities available after graduation. Agency representatives will be available from 5:30 p.m. to 7:30 p.m. to speak with the attendees. The location for the Transition Fair is at Mall of the Mainland, 10000 Emmett F. Lowry Expressway, Texas City, TX [Exit # 16 off I-45].

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 C.A.M.P. 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
- Newsletter Editor: Edit and publish our newsletter six times per year
- Adult Programs Committee Chair: Design and kick-off our programs for teens and adults

- Golf Tournament: Help organize our Spring golf tournament

Volunteer to be on a committee:

- Fundraising
- Outreach
- New Parent
- Public Relations

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



CafePress T-shirt

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

The deadline for submissions to the April newsletter is March 15.

Greater Clear Lake
Families Exploring
Down Syndrome

Phone
(832) 457-2775

E-mail
gclfeds@clearlakeds.org

Website
www.clearlakeds.org



A Little Inspiration

Are you looking for inspiration as you shop for a Valentine's day gift for that someone special? Try the CafePress website – a clearinghouse for vendors of T-shirts and other gifts including Down syndrome T-shirts, coffee mugs, tote bags and other items with slogans like "Someone with Down syndrome Loves Me" (www.cafepress.com).

To narrow your search for toys for the special child in your life, check out the Toy Industry Foundation's guide "Let's Play, a Guide to Toys for Children with Special Needs." The guide features hundreds of toys tested by children with special needs and includes a description

of each toy and the skills that the toy will build during playtime (<http://www.afb.org/Section.asp?SectionID=82>).

Need help with medical care not covered by insurance? The UnitedHealthcare Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by the available commercial health benefit plan. <http://uhccf.org>

Thank You!

Our gratitude and thanks to the following generous donors:
Jaci Vawter & family – donation for December social

Kroger – donating supplies and a cake for our October meeting

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

- Jaci Vawter – organizing the fun December social
- Girl Scout Troops 7028 and 1841 – providing activities for our kids at the social and sharing their Christmas spirit

- Doug Broom – making sure that Santa Claus made it to the social!
- Elizabeth Stevens, Neesha Hosein, Beth Haas, Alicia Dague, Anne Bernay, Tracy Kachtick-Anders, Melissa & Keith Collins – writing for our newsletter this month
- Elizabeth Stevens – assisting with newsletter editing
- Linda Gellman – providing our members with information on school evaluations at our January meeting

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.