

GREATER CLEAR LAKE Families Exploring Down Syndrome

Calendar of Events

April

- 17 Monthly Meeting
TalkTools
Jenn Buck, SLP
6:30 pm Pizza & talk
7:00 pm Speaker
United Way-Bay Area Bldg.
1300 Bay Area Blvd.
Conf. Room A. Child care provided.

May

- 9 Golf Tournament
8 am Tee Time
Timber Creek Golf Club, Friendswood
Register Online!
- 17 May Social
3 – 6 pm
Challenger Park Pavilion #3
Bring a dish to share

June

- 18 Monthly Meeting
Potty Training
Tracie Frederick, Rise School teacher
6:30 pm Pizza & talk
7:00 pm Speaker
United Way-Bay Area Bldg.
1300 Bay Area Blvd.
Conf. Room A. Child care provided.

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Home from the Hospital – What Do We Do Next?

By Anne Bernay & GCLFEDS Moms

So you're home from the hospital and the family is settled in with the new baby. After finding out your child has Down syndrome, dealing with doctors and specialists and explaining to family and friends, you are exhausted...and probably worried. Do you know everything you should to provide the best resources and support for your child? Are you doing everything you need to be doing?

This can be a scary time, but parents who have gone through this have advice for new parents to make it less frightening. Members of GCLFEDS shared the things they wished they had known as a new parent and the things they learned along the way. All said that the most important thing to remember is that you have plenty of time. Just take things slowly and remember to enjoy being a new parent. Your little bundle of joy needs your love and attention – the rest can

come later!

Baby First!

"I think one of the most important things for new parents to remember as they gather resources—emotional and otherwise—after their baby is born, is to enjoy their new baby. I definitely got caught up in the doctors' appointments, which therapies I was supposed to get my son into and when he would reach various milestones. Enjoying that precious bonding time with your baby cannot be overemphasized. When in doubt, snuggle, snuggle, and then snuggle some more!"
Cristen Reat, mother of four-year old Vincent, advises.

Vincent's 7 ½-year old brother, Martin, adds, "At night I like to snuggle with Vincent in his bed. Sometimes it's hard having a brother with Down syndrome because he makes a loud sound I don't like very much when I'm

trying to play with him. Sometimes it's easy to play with my brother because he does funny word games with me. Also when Vincent was born and was trying to sit up, I put a pillow behind his back so if he fell, he would land on a soft object."

Judy Hile's daughter Tracy is now an adult, but she still recalls how Tracy was the same as any other baby at the same age. She feels it is important to go and do exactly the same activities you would have done if the baby didn't have Down syndrome. "We had planned a camping trip in a 'pup' tent with friends. We went ahead with our plans and took Tracy. She was 6 weeks old!"

Get Support from Other Parents

"What I did during the first six months was read and look up information about Down syndrome,

Continued on page 5



Peter, age 5, and Cowboy Kevin at the Lil' Rustlers Rodeo, March 2008

From the Prez

Last week I attended the Wrightslaw Conference put on by an autism group on the northwest side of town. My son, Peter, will start kindergarten in the fall and we've started the preparations with the school - evaluations, IEP development, and meeting school personnel. Having gone through the ARD process for the past three years and attended numerous classes and conferences, I was beginning to feel like an old pro. Listening to Pete Wright at the conference (and

also Joanie Garro at our February meeting) made me realize how much I DON'T know!

That's why I am so grateful for the amazing volunteers and members who are "exploring DS" with GCLFEDS. There is so much to know and learn, so much that is changing in areas like education and medicine, and so little time to educate yourself as a parent! Each of us brings different experiences, different knowledge and different passions to the

table. Sharing our knowledge, lending support to other families, and educating the community, we can together make the "exploration" a little easier, the path a little less confusing.

Enjoy our first newsletter and please give us feedback. The website continues to evolve, so check that out every once in a while. And join us as GCLFEDS continues to grow and explore the wonderful world of DS! Anne

Board Meeting Minutes - February

The GCLFEDS Board of Directors met on February 7, 2008. Following up on our January planning meeting, we reviewed a new progress report that will help us keep on track in meeting our goals for the year.

Tiffany Novick and Lillie Monita are well on their way to developing our very own New Parent Packets, which will be distributed to new parents along with a gift

for baby. Beth Haas, Outreach Chair, has put together packets for doctors and medical professionals with relevant, up-to-date information for the professionals as well as info to be given to parents. These will be distributed to doctors' offices and hospitals in our area.

The GCLFEDS Education Plan is in full swing under the very talented

direction of Dr. Denise Chapman and Joanie Garro. This effort will help us as parents and assist our educators as well.

The Board agreed to begin video taping our monthly meetings and making them available on the members' page of our website, with a target roll-out of that page in March.

Golf tournament planning was discussed in detail.



New member, Kyle, age 3

Board of Directors & Committees

President	Anne Bernay	pres@clearlakeds.org	832-457-2775
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New Parent	Tiffany Perez	newparent@clearlakeds.org	
Webmaster	Joel Burdeaux	joelburdeaux@gmail.com	

1st Annual GCLFEDS Golf Classic



Get out your clubs and get ready to hit the links! The 1st Annual FEDS Charity Golf Classic needs your support.

Timber Creek Golf Club in Friendswood will be the site of this GCLFEDS fundraiser on Friday, May 9. Golfers will tee off at 8 am for a four-person scramble. Prizes will be awarded for the closest-to-the-pin, longest drive and top two team gross and net scores. The registration fee also includes a light

breakfast, lunch, a team picture, range balls, and cart.

We encourage all GCLFEDS members who are golfers to play in the tournament. GCLFEDS members can also help by recruiting golfers, obtaining sponsorships and volunteering at the tournament.

Hole signs can be purchased to honor your child or adult with Down syndrome. This is

a great opportunity for grandparents, aunts, uncles and friends (even if they live out of town) to support the event as well.

All funds from this event will support GCLFEDS programs. One program in the development stage that will move forward with this funding is a scholarship program for graduating high school seniors. New parent support packets, information for medical

professionals, and our fall conference are other programs that will benefit.

Register online at www.clearlaked.org or mail in the registration form available on the webpage. If you can help with the tournament, please contact Anne Bernay or any GCLFEDS Board member.



GCLFEDS Education Effort

Ensuring their child gets the best possible education is a high priority for our members and any parents of a child with Down syndrome. GCLFEDS is committed to helping parents as they individually address education issues but is also undertaking an effort that will benefit our entire membership.

GCLFEDS' Education Effort has two primary areas of focus:

- Establishing relationships with our local school districts
- Influencing teacher training

Establishing relationships with our local school districts will allow GCLFEDS

and its members to get better information about district special education and how it affects our children. It will also enable us to have a more direct and proactive impact on addressing issues and providing support to the districts. We hope to develop a mutually supportive atmosphere in the districts that will enable both sides to work issues for the ultimate benefit of our children.

Several initiatives are underway to provide information to parents as well as students in the UHCL Education program. We are

pursuing grants to develop several videos that will focus on the ARD process and give both parents and teachers a chance to see what works and what doesn't. GCLFEDS families have also volunteered to let UHCL students attend their children's ARD meetings so that they can experience the ARD process first-hand before they have to attend as a teacher. Lastly, plans are underway for several of our meetings to address education issues for both parents and students from UHCL. We were so fortunate to have about 15 students

attend our February meeting, ARD 101.

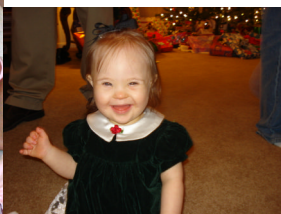
Look for more information on GCLFEDS' efforts in the education area in future issues and on our website.

Special Education Tip

Want to get a better understanding of IDEA 2004 special education law and how it applies to your child? Check out www.wrightslaw.com/idea/index.htm or Wrightslaw Special Education Law, 2nd Edition by Peter Wright and Pamela Wright in the GCLFEDS library.



Amara, age 2
Adrian, age 22 months



Macie, age 1



Darin, age 2



The Gressett Family

Welcome New Members!

Thank you for supporting GCLFEDS.

Anderson Family – Jennifer, Ryan & daughter Macie, 1

Bostelman Family – Richard, Sylvia & son Joshua, 3

Burdeaux Family – Joel, Heather, daughter Arabella, 6, & son Darin, 2

Ebert Family – Marlei, Doug & Amara, 2

Gressett Family – Kevin, Jamie & son Chance

Henicke Family – Erica, Jeremy & son Carston, 5

Jolivet Family – Chris, Natalie & son Kyle, 2

Monita Family – Chris, Lillie & son Adrian, 22 months

Reat Family – Cristen, Daniel & son Vincent, 4

Stevens Family – Bill, Elizabeth & daughter Claire, 6 months

Trahan Family – Andy, Angela & son Ashton, 5

Become a member today!

Register online at www.clearlakedcs.org or mail the form available on the website.

Meet Our Member: Joseph Novick

Joseph Samuel Novick was born on April 26, 2005 in Corpus Christi. A very friendly little boy, he likes listening to music, dancing, playing with Elmo toys and eating yogurt. Joseph enjoys playing with his siblings: Celeste (4) and Aaron (6). He also visits older sisters Mariah (16) and Olivia (15) at Grandma's house in Austin.

Joseph's mom had a normal pregnancy but had to have an emergent C-section when Joseph had distress during labor. His Down syndrome was not diagnosed for a few days after birth, as he didn't show all of the typical features. He did have fever and jaundice and spent the first few days of life in the Neonatal ICU. Otherwise, he was a healthy baby.

Joseph grew and



developed well as a happy baby until one weekend in November 2006, when he became irritable and had fever. His doctor noticed a rash, and blood tests showed he was low in platelets. He developed a tender swollen foot, and was sent to Texas Children's Hospital, where further blood tests and bone marrow biopsy showed that he had myelodysplastic syndrome (MDS), an illness similar to

leukemia (AML). At first the doctors thought Joseph would need bone marrow transplant, but recent trials had shown an effective course of chemotherapy for children with Down syndrome who get AML or MDS. Over the course of eight months, he received several cycles of chemotherapy, spending a total of about four months in the hospital. Further tests showed his disease to be in complete remission, and he is down to bimonthly

oncology follow-up visits. Joseph's hair has grown back, and he is back to being himself except that he is a fussier eater now.

Joseph has had therapy since birth from ECI, with recent supplementation from St. John's, and we will soon be meeting with Clear Creek ISD officials to develop his plan there. Present developmental tasks we are working on include eating more solids and communicating. After Dr. Jim McDonald's visit (GCLFEDS November 2007 conference), Joseph spends most of his time at home with mom to maximize interactive communication time.

Joseph likes babies, which will come in handy this summer as he welcomes his new baby brother. His mom, Tiffany, is our New Parent Coordinator.

Home from the Hospital, continued

Continued from page 1

because I didn't know what it was and that was scary to me," says Lilliana Monita, mother of 22-month old son Adrian. "The next best thing I did was join a parent support group and attend their meetings. There I had the chance to talk to other parents and ask questions. I learned many of the next steps I needed to take to help my son, who is truly a blessing to our family."

Start Early with Medical Care and Therapy

Learning about medical issues, scheduling and going to doctor appointments, and caring for medical problems at home can feel overwhelming during the first several years. Parents find themselves in the position of deciding which doctors to see with very little information. They may have to make decisions about treatments while weighing whether the doctor is being conservative or aggressive, whether a second opinion is needed, and what is, of course, best for their child and family. And when the doctor has little experience with children with Down syndrome, the parents are often in the uncomfortable and

scary position of guiding and educating the medical professional.

"I would recommend getting a copy of the American Academy of Pediatrics Health Supervision for Children with Down Syndrome. It is meant to be a guide for pediatricians as they treat children with Down syndrome, however, it is a great resource for parents," explains Beth Haas, mother of three-year old Annalee. "By reading it yourself and providing a copy for your child's pediatrician, you are increasing the chance that nothing will be overlooked as your child attends their well child visits."

Patty Cortez, mother of two-year old Crystal, adds, "One thing that really surprised me, and I was sad that I did not do, was to get Crystal's vision checked at a much younger age. I learned that I should have gotten her vision checked starting at 6 months!" Most parents also do not realize that they may have to push the optometrist to treat vision problems aggressively at a young age. Unless the optometrist is well-educated about kids with Down syndrome, he or she may not realize that many kids

with Down syndrome are attending school at a much younger age than their typical peers and starting Early Childhood Intervention at birth. All of these activities require good vision, and without aggressive treatment of vision impairment, development of speech, fine motor and gross motor skills can be hindered.

Speech is one of the challenging areas for children with Down syndrome and the earlier the child begins speech therapy the better. "Call your insurance carrier to find out what coverage you have for speech therapy and find the best certified speech pathologist you can," recommends Angela Trahan, mother of Ashton, age five. "Learn your benefits for coverage for your child inside and out and also know your appeals rights." Whether speech therapy is provided by ECI or you arrange for private therapy, start early to give your child the best foundation for speech.

Most parents are referred to Early Childhood Intervention (ECI) by their doctor or hospital right after their child is born. ECI is a statewide program for children with



Vincent, age 4

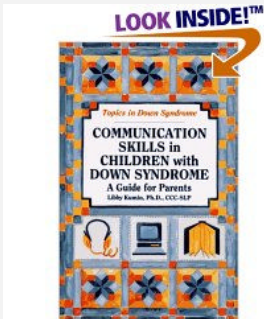
Resources

Greater Clear Lake Families Exploring Down Syndrome:
www.clearlakeds.org

American Academy of Pediatrics Health Supervision for Children with Down Syndrome:
<http://aappolicy.aappublications.org/cgi/reprint/pediatrics.107/2/442.pdf>

DARS Inquiry Line for ECI Referrals: 1-800-628-5115

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This book is available in the GCLFEDS library. Check it out at the next meeting or request it via our website, www.clearlakeds.org.

"Remember to take care of yourself."



GCLFEDS moms enjoying a break at Mom's Night Out

Book Review

Communication Skills in Children with Down Syndrome - A Guide for Parents by Libby Kummin, PhD, CCC-SLP

From Library Journal
The ability to communicate effectively is critical to the happiness of all children but may be particularly challenging for a child with Down syndrome. This work, an excellent supplement to a previous compilation, Babies with Down Syndrome (Woodbine

House, 1986), focuses specifically on how parents can maximize the communication skills of a child with Down syndrome. Speech and language pathologist Kummin traces the development of communication skills from infancy through early adolescence, describing the problems that might arise during each stage and suggesting a wide range of home-based activities to help. Also discussed are the formal and informal methods of evaluating

a child's communication ability, the interpretation of test results, and the range of professional services available. Each chapter concludes with an excellent annotated resource guide. This comprehensive and supportive text is highly recommended for parenting and health collections.
- Linda Cullum, Lake Superior State Univ. Lib., Mich. Copyright 1994 Reed Business Information, Inc.

Home from the Hospital, cont.

Continued from page 5
developmental delays, birth to three years, and will provide services in your home. If you have not been contacted by ECI, call the DARS inquiry line at 1-800-628-5115 to refer your child.

Get on Waitlists for Services

It's difficult to imagine your child's future when she is a tiny infant and even more trying to imagine her future after you and your spouse are gone. But parents of children with Down syndrome must do just that so that their child is eligible for adult services by the time she is grown. In

addition, there are services that may be provided while the child is still young.

The infamous "Waitlists" refer to the interest lists for Medicaid waiver programs provided by various agencies such as the Department of Aging and Disability Services (DADS) and the Mental Health Mental Retardation Authority (MHMRA). A Medicaid waiver program is one that qualifies an individual for Medicaid and the special benefits associated with that program, even though their family resources disqualify them for Medicaid through SSI (Supplemental

Security Income). There are many programs available and each has their own process, benefits and interest/waitlist. They also have different qualifying requirements. A summary of the program names, agencies that administer them and their phone numbers are in Table 1 (pg. 7).

Some of the Medicaid waiver waitlists are VERY long – over ten years. So it is important to get on the waitlist while your child is an infant. You can decide once your name comes up whether you actually need or want
Continued on page 7

Home from the Hospital, cont.

Continued from page 6 the program. But unless you have a very accurate crystal ball, you won't know that until the time comes. And why risk not having the resources you need to give your child the life they deserve?

Get on School Waitlists

"It is important to get on waiting lists for special schools such as The Rise School of Houston and The Arbor School as soon as you can. Many times there can be a wait of three or more years," notes Ellen Lachney, mother of Shelby, age 4. Even if you are unsure whether a special school is right for your child, it gives you the opportunity to take

advantage of it once your child's name comes to the top of the list. Many people cannot imagine sending their infant to school, but as you become more familiar with the other resources available and understand better what developmental support your child needs, you may feel differently. Do not get discouraged by the long wait. Even if your child is 3 or 4 years old by the time he starts, he can still benefit greatly from the programs and curriculum of the special school. "My child got into The Rise School at age 3 and has grown tremendously in the last year and a half since starting," says Ellen.

Some of these schools even offer support and resources for parents while they are on the waiting list.

Take Care of Yourself

Board member Joanie Garro, sister of Joey Garro, says, "Remember to take care of yourself. Schedule date nights, quiet baths, or take a walk in between appointments."

It's so easy to get focused only on what you need to do for your child. But realizing that you can take your time and balance Down syndrome issues with normal family life is perhaps the most important thing that parents can do for themselves – and their child.

Resources

The Rise School of Houston: 713-532-7473; www.riseschool.org

The Arbor School: 713-827-8830; www.arbor.org

Program Name	Process	Interest List
Community Living Assistance and Supportive Services (CLASS) <ul style="list-style-type: none"> Helps with activities of daily living if living by self, with family or with 3 or less other people with disabilities 	<ul style="list-style-type: none"> No paperwork needed Call to get on list Waiting list 10 years+ 	DADS 1-877-438-5658
Home & Community Based Services (HCS) <ul style="list-style-type: none"> Helps an adult live at home or in group home 	<ul style="list-style-type: none"> Call to get on waiting list 	MHMRA (Harris County) 713-970-7799 MHMRA (Galveston/Brazoria) 1-800-643-0967
Medically Dependent Children Program (MDCP) <ul style="list-style-type: none"> Provides respite care 	<ul style="list-style-type: none"> No paperwork needed Call to get on list 	DADS 1-877-438-5658
Children with Special Health Care Needs (CSHCN) <ul style="list-style-type: none"> For children with chronic physical condition 	<ul style="list-style-type: none"> Call for application Must reapply every 6 months 	DADS 713-767-3111 1-800-252-8023
In Home and Family Support (IHFS) <ul style="list-style-type: none"> Can cover expenses related to the disability not covered by insurance 	<ul style="list-style-type: none"> Must get diagnosis of MR first Waiting list 4-6 months 	Diagnosis of MR 713-970-7100 IHFS 713-970-7229

From hand-out by Heather Burdeaux for GCLFEDS meeting March 2007

Table 1: Medicaid Waiver Program Waitlists

A Little Inspiration

Students at a Mexican school for people with Down syndrome are producing paintings and lithographs that are impressing connoisseurs and shattering preconceptions about mentally disabled people. See <http://www.azcentral.com/news/articles/0210od4.html> for more info.

Mr. Blue Sky DVD is now available through the film's website www.mrbueskymovie.com. The story of Mr. Blue Sky is a heart-warming love story, which is as much about hope for children born with Down syndrome as it is an inspiration for all children born with any intellectual or developmental challenges.

Dr. Wonder's Workshop Saturdays, 11 a.m. Ch. 14 (TBN) www.drwonderinfo.com Christian role models share life-changing truths with your children in sign language, English, and captioned Spanish. Great to inspire a new understanding & help teach sign language.

Thank You to Our Sponsors & Volunteers

Our gratitude and thanks to the following donors to our monthly meetings:

- Alicia Dague – dessert for January meeting
- Megan Starr – dessert for February meeting



- pizza for our February meeting

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

- Beth Haas – putting together our packets for hospitals and doctors
- Tiffany Novick and Lillie Monita – putting together our New Parent packets
- Beth Haas and Anne Bernay – representing GCLFEDS at the LaPorte High School Tomorrow's program
- Joanie Garro, Denise Chapman and Anne Bernay for speaking at the Gulf Coast Transitions Task Force meeting

Greater Clear Lake
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Syndrome

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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.