

G R E A T E R C L E A R L A K E

Families Exploring Down Syndrome

Calendar of Events

February

- 17 **Hearing Loss and your child***
By Kristi Ferguson
- 19 Play date
League city, boundless playground
- 24 Mom's night out

March

- 11 **Couples night out**
- 19 Play date Frankie
Carter Randolph Park
- 24 **Plan your child's future***
by Kim Hegwood
- 31 Mom's night out

April

- 9 Dad's night out
- 14 **To be announced***
- 16 Play date Frankie
Carter Randolph Park
- 28 Mom's night out

*** 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.

RSVP:

www.clearlaked.org

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T21 Conference 2011: informing and empowering

"We are more alike than different." With this beautiful statement, Christie and Austin Hockel Davenport ended their impressive speech. The audience, laughing a lot, crying a little, gave the couple a standing ovation. Christie and Austin, both in their thirties with Down syndrome, were married a year ago and live in Dallas. They have jobs and live as independently as possible. On February 6, 2011, the couple opened the T21 conference in Houston and inspired 160 attendees for the day and for the future.

'T21: Down syndrome in the 21st century' is a yearly conference for teachers, parents and medical professionals of the greater Houston area. It is organized by a group of six organizations, including GCLFEDS. 160 People spent the day listening to and discussing the possibilities for children and adults with Down syndrome.

The conference was built up around three strands: medical, educational and parental. After Christie and Austin finished their opening speech, the attendees were invited to go to the workshops of their interest.

Co-teaching

The morning program of the educational strand was dedicated to co-teaching. Kimberly Baumgardner and Lisa Kirby, education specialists from San Antonio, explained this new way of teaching.

Co-teaching is when two or more teachers, one a general educator and one a special educator, share a classroom in order to actively instruct a blended group of students, including students with disabilities. The idea is to bring services to the students, instead of pulling them out.

The speakers emphasized the shared responsibility and shared ownership the teachers have for the class ('these are OUR children') and the need to communicate between them. The general ed teacher will have to accept different levels of learning in the class. The special ed teacher has to let go of his or her feelings of protection ('they are my babies') and has to learn to keep up with the planning of the general curriculum.

The speakers discussed different co-teaching approaches and the different stages of co-teaching. They stated that research shows co-teaching will never lead to watering down the general curriculum, a common fear of general educators.



Texas school system

In a Q&A-session within the parental strand, three experienced parents (Jan Stalley, director of Rise School, Kristin Tassin, director and founder of Father's Joy, and Jennifer Wrzyszczyński from DSAH) answered questions from the audience. Different issues entered the floor.

Would you advise to hold back your child? Of course this depends on the situation, but Kristin Tassin gave as a general note that our children will never meet the general curriculum requirements. Modifications will always be needed. Therefore social aspects should be an important factor in the decision to be promoted or retained.

The next issues brought up were IEP goals and ARD meetings. Choose your battles, be prepared, know your child, be creative and build a relationship with your school were the most important recommendations given. "Losing your temper at the table is very wrong", Mrs Tassin told from her experience. Parents have the power to suggest changes and say no during ARD meetings. From the audience there was the suggestion to get a health impairment form signed by your pediatrician to make it easier for your school to organize aides and support.

Respiratory Complications

Dr. George B. Mallory, Jr., Assistant Director of the Pediatric Lung Transplantation Program at Baylor, gave a speech within the medical strand. Dr. Mallory discussed respiratory complications that may arise in patients with DS, due to incomplete development and abnormalities in the respiratory tracts and immune systems that make our kids more vulnerable to sleep apnea, pulmonary hypertension, pneumonia and other complications. His advice to parents: "Do not accept substandard care." He suggested a proactive approach including giving our children the pneumonia vaccine and seeking out evaluations for symptoms associated with sleep apnea.

To be continued on page 8

A Special Thank You to Our Departing Officers, Directors and Committee Chairs:

Education Advisor Joanie Garro served three years on the Board, and was instrumental in creating the Explorer Awards and directing Film Club, as well as educating us as a speaker at several monthly meetings. Treasurer Melissa Collins served in her position for two years and assisted with many events during her tenure. Alexis Marchenko handled Public relations for GCLFEDS during 2010. Joel and Heather Burdeaux did a terrific job creating and maintaining our original GCLFEDS website, putting in countless hours creating pages and updating information for us. All will be very much missed!

Our Returning Board Members and Committee Chairs:

Our returning officer is Alicia Dague, who has served as Secretary since GCLFEDS' inception, and will continue as Secretary and Chair of the Membership and Step Up Walk Committees. Past President Anne Bernay will serve as Chair of the Education and Governance Committees. Returning Committee

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

New board members by Anne Bernay

As an all-volunteer non-profit, GCLFEDS relies entirely on its volunteers. We are very fortunate to have a group of dedicated, talented individuals at the helm for 2011. Meet the new officers and committee chairs:

2011 President and Webmaster Vince Johnson In 2010, Vince was a key member of both the Golf Tournament and Step Up Walk committee. He showed his prowess at fundraising by acquiring raffle items and prizes, convincing co-workers and friends to participate in the events, and working at the events himself. His interest and talent at website design was put to good use managing the Step Up Walk website as well as identifying a new system with increased functionality for the GCLFEDS website. Vince is currently the Director of Annuity and Pension Systems for American National Insurance. He is the father of Morgan, age 4 with Down syndrome, and Madison. Vince wants "to ensure the ongoing success of GCLFEDS."

2011 Treasurer Blanka Brhlik is a busy volunteer, dental hygienist, and mom to Sarah, age 11 with Down syndrome, and David. Blanka has assisted many non-profits with fundraising and programs, Blanka worked on GCLFEDS' Wine Tasting Committee in 2008 and has supported many of our efforts over the years. Despite living across town in Sugar Land, Blanka will assume the Treasurer position to help "continue the work of this impressive organization."

2011 Outreach Chairperson Jacquelyn Ingram is owner of Gimme A Break, which provides hourly childcare and preschool in Webster. She is the mother of Kevin, age 9 with Down syndrome, and Kyle. Jackie captained Kevin's Cowboys, the Step Up Walk team that won the awards for Biggest Team (110 walkers) and Highest Team Fundraiser (\$6,830). Jackie has experience speaking to local schools about Down syndrome and can't wait to help GCLFEDS educate our community about DS and the abilities of individuals with DS.

2011 Newspaper Editor Silvie Warmerdam moved to the Clear Lake area a year ago and immediately got involved in GCLFEDS. She and her family are natives of the Netherlands. A mother of three boys, including Daniel, age 6 with Down syndrome, Silvie spends her "free time" writing articles for Dutch newsletters and blogs about what living with Down syndrome is like in the U.S.A. She has the perfect skill set to be our newsletter editor, but asks for understanding if her English isn't perfect!

2011 Golf Tournament Chairperson John Haas is a NASA employee, training astronauts at the Neutral Buoyancy Laboratory. John was a member of the Golf Tournament Committee in 2010 and has supported the event since its inception in 2008. Father of three girls, including Annalee, 5 with Down syndrome, John has been involved with GCLFEDS since his wife, Beth, helped found the organization in 2007.

Board of Directors

President	Vince Johnson	pres@clearlaked.org	281 412-9958
Vice President	Open		
Secretary	Alicia Dague	sec@clearlaked.org	832-275-9365
Treasurer	Blanka Brhlik	treas@clearlaked.org	281-303-5611
Director	Dr Ostermeier (medical)		
Director	Anne Bernay	education@clearlaked.org	832-457-2775

Committees

Outreach	Jacky Ingram	outreach@clearlaked.org	281-554-5000
New Parent	Cristen Reat	newparent@clearlaked.org	
Newsletter	Silvie Warmerdam	newsletter@clearlaked.org	281-982-7545
Social	Tiffany Novick	social@clearlaked.org	281-339-1373
Librarian	Laura Johnson	library@clearlaked.org	281 412-9958
Meetings	Beth Haas	meetings@clearlaked.org	281-486-0898
Webmaster	Vince Johnson		

Planning meeting 2011 by Alicia Dague

Saturday January 29, the board met to discuss the planning for 2011. With laptops, internet, coffee, fruit and brownies, we talked about GCLFEDS in its fourth year.

Goals

With new board members and a new president, the start-up period of GCLFEDS comes to an end. GCLFEDS is a growing organization with routines, like the monthly meetings, settled and enough money on the bank to make new steps.

The board decided as goals for 2011: to become more visible in the community, to enhance the service for members and to continue the successful monthly meetings.

More visible in the community

- Enlarge the efforts to contact hospitals and do presentations for nurses and doctors. To open doors, GCLFEDS will develop a basket for parents of newborns..
- Work on a plan to get Down syndrome specialists into the school districts. Those specialists should be able to help teachers to educate our kids the best way possible. GCLFEDS will work together with DSAH on this plan.

Enhance service for members

- Launch the new very interactive website to serve the members in a better way:
www.clearlaked.org
- Update the newsletter into an email newsletter which will be easy to read on the screen with links and 'read more' options.
- Create a Facebook page.
- Structure the social events and organize them more in advance. Organize social events for teens and adults with Down.
- Publish a calendar for the year 2012 with pictures of the walk of 2010; the board is looking for someone who wants to organize this.
- Add Music Therapy workshops in addition to the sign language workshops: free for members.
- Send out a member survey to get a better understanding of what members want.
- Reorganize the GCLFEDS library
- RSVP for monthly meeting child care to ensure sufficient childcare; members will go first.

Want more to know more about the 2011-plans? Email Vince Johnson: pres@clearlaked.org
Interested in the minutes of the meeting? Ask Alicia Dague: sec@clearlaked.org

Golf tournament by John Haas

We look forward to another fun day playing in our 4th Annual GCLFEDS Golf tournament this year. The date is set for May 20, 2011. Last year's tournament was such a success that we decided to go again with Southwyck Golf Club located in Pearland.

I am trying to fill some big shoes by chairing the Golf Committee this year after three years of growth under the direction of Anne Bernay. Anne is continuing on as a board member to ensure a smooth transition and provide continuity. MG and Nancy Spanial are helping again this year and Vince Johnson manages the web site. It's very exciting to have some new people serving on the Golf Committee: Sharon and Heidi Harrelson (grandmother and mother of Austin), Dick Sauer (Grandfather of Annalee Haas) and Lisa Spence and Susan Sinclair and are all volunteering their time and energy. Lisa and Susan do not have any family members with Down syndrome but they have watched Annalee growing up. It's really nice to have some non-family members getting involved with GCLFEDS.



We will build on last year's raffle. The raffle was a good fundraiser and it's a very convenient way for people to help out even if they don't golf. We are currently trying to line up prizes so we can start selling tickets on March 15. If you would like to sponsor a raffle prize or know someone who would please contact me (or any committee member) using golf@clearlaked.org.

Please encourage folks to enter the tournament. Doing so early gets it on people calendar and usually garners more success. Find all the information on www.clearlaked.org/Golf.

Cognitive research by Silvie Warmerdam

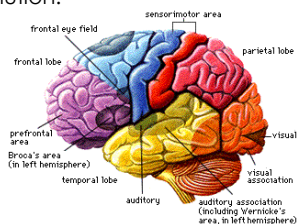
During the monthly meeting in January, many members of GCLFEDS came together to learn about Down syndrome cognitive research going on at different Universities. Dr Robert Schoen presented the work of the Research Down Syndrome Foundation (RDS). He talked about drug targets and successful studies on mice. RDS is a charity that funds research with the aim to develop drugs to enhance the cognitive abilities of people with Down syndrome.

Clinical tests

Dr Schoen's presentation is a plea to spread the word. In order to be able to continue the important work, the researchers need more funds. As Dr Schoen explained: "The last five years we made great advances towards developing biomedical therapies to treat the cognitive impairment of people of all ages with Down syndrome. We have detected drug targets, we tested medicines on specially prepared mice. The next step will be clinical trials on human beings. Those clinical trials are very expensive; we are in need of big money to be able to continue our work."

The aim of the research is to develop drugs for all people with Down syndrome to enhance their memory and cognitive abilities, without changing their personalities. According to Dr Schoen, the goal is to provide greater opportunities for people with DS: "We don't say you need to give your child those drugs, but we want to enlarge the options for them. We want to broaden the possibilities for an independent life, for jobs and education."

Paul Watson, parent of a son with DS, who served as Dr Schoen's side-kick during the presentation, added: "Inclusion, education and early intervention have brought our kids a long way. But now we're facing their chemical boundaries. To provide medicines is the next step and it is our duty to stand up for these possibilities and support this revolution."



Unity needed

The need to focus on funding for DS research is made apparent by a simple comparison: the amount of funding for research on autism is six to eight times that of Down syndrome research. As Mr. Watson explained: "The autism community understands how to make one voice. They spent more than \$900,000 on lobbying last year; NDSS spent \$15,000. The Down community needs to unite, to show the pharmaceutical industry that there will be a market for these kinds of drugs." One way to speak with one voice is a petition Paul Watson prepared for the National Institute of Health (NIH), to ask for a shift in the way research money is spent. GCLFEDS signed this petition. RDS has a dual mission. Besides funding research, the charity wants to raise the awareness of the general public about the need for Down syndrome cognitive research.. They make presentations to organizations like GCLFEDS, and are using social media networking, email messaging and will be conducting a direct mail campaign in the near future. Watson is striving to build a huge network to connect people and money, and hopes that the network will include high profile people as well. He answered the obvious question at the meeting: "Yes we are in contact with Sarah Palin, I spoke to her and her husband face to face. But they are very busy and everybody is pushing them, we have to wait and see. There are more famous people around who might want to help." Both Dr. Schoen and Mr. Watson conveyed their enthusiasm for the possibilities in improving the lives of people with DS through the development of drugs to enhance their cognitive abilities.

*Special thanks to
Elizabeth Pool for editing*

**Next Monthly meeting:
February 17
'Hearing loss and your child'
By Kristi Ferguson, M.Ed, CED**

Want to know more?

Research for Down syndrome:
<http://www.researchds.org/>
On the website you'll find two video's to share with friends and family. You also can learn more about the technical and chemical part of the research. The slides of the presentation are to be found [here](#).



The speakers:

Dr Robert Schoen, PhD, is President of Research Down Syndrome. Dr. Schoen received his Doctorate from the University of Texas Medical Branch at Galveston in Human Genetics/Cell Biology. Email: info@researchDS.org

Paul Watson, father of an eight year-old son with Down syndrome, works as a fundraiser and collaborative partner with researchers and charities. He also serves on three Texas state committees for special education. Email: pjwatson@yahoo.com

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

6:30 pm
Pizza and informal
discussion
7:00 pm
Speakers

Child care provided:
please RSVP

meetings@clearlaked.org

Bayler College of Medicine organizes evening seminar about different topics around people with disabilities Check out their [website](#)



Would you like to know more?

Find here the program of the conference and an overview of the different sessions: <http://www.dsaia.org/joomla/index.php/sessions.html>

If you have any questions or comments about this event, please e-mail Vince Johnson at pres@clearlakeds.org.

Medicaid Buy-In by Silvie Warmerdam

Medicaid Buy-In is a new program designed to help families receive Medicaid for their special needs children without requiring them to give away all of their resources or quit a job. If your child does not have insurance or if you have insurance but need additional coverage, Medicaid Buy-In might work for your family. The program rolled out on January 2, 2011 and a family of four making up

to approximately \$62,000 will be eligible. A Medicaid/HHSC worker can help you determine if you are eligible.

For more information, call your local HHSC (Health and Human Service Commission) office: 10060 Fuqua, Houston TX, 77089. Phone: 713 946 6861. Or look at:

<https://www.yourtexasbenefits.com/ssp/SSPHome/sspHome.jsp>

Find more information here:

<http://www.hhsc.state.tx.us/Help/Heal>

DSAIA Conference by Vince Johnson

Besides being an affiliate of the National Down Syndrome Society (NDSS), GCLFEDS is also a member of Down Syndrome Affiliates In Action (DSAIA). DSAIA started as a conference bringing together leadership from Down syndrome organizations around the country. After consecutive years of explosive growth, the conference has extended its reach internationally and is now a trade association continuing its mission. Its goal is to bring together Down syndrome organizations from all over the country, to share, learn and connect.

As a trade association, DSAIA has been able to create relationships with many different service providers to offer its member organizations discount on various books, software, insurance, t-shirt orders and web-tools. For example, DSAIA's affiliation with a software

company called EZ Event Solutions led to the creation of the fundraising software utilized by GCLFEDS for the Step Up Walk, giving us an easy and cheap tool for managing our 2010 event.

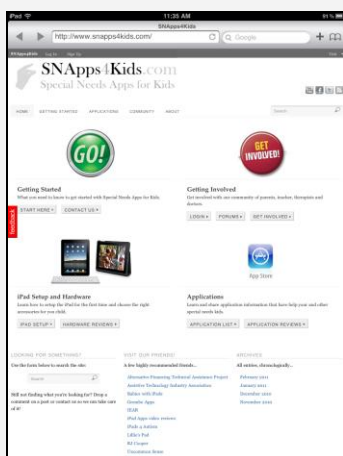
Each year, DSAIA holds a conference for all of its member organizations to get together and discuss the issues and opportunities they face. Last year Anne Bernay and Alicia Dague went and came back with a lot of new ideas and a long wish list: "We still have wishes on our list from that visit and notes we have to share with our members," tells Anne during the board meeting. "We met so many people who inspired us, it was great", Alicia adds. The 2011 conference is in Dallas, from January 24 till 27. Anne Bernay will go again with Vince Johnson, our new president.

The world of apps by Silvie Warmerdam

Apple has highlighted a growing number of apps catering to individuals with special needs with a featured special education section in its App Store. The section titled "[Special Education](#)" includes applications for the iPhone and iPad in 10 categories ranging from communication to emotional development and life skills. Apps, which can be used on Apple's iPhone, iPad or iPod devices, have become increasingly popular in the

special needs community in recent years, serving as everything from assistive technology devices to organizational tools and teaching aids. (Source: [Disabilitycoop](#))

In the Houston area a group of parents, teachers, therapists and doctors have organized themselves to discuss the available apps. The group is called 'snapps4kids'. There is a newsletter and monthly gatherings. More info on <http://www.snapps4kids.com/>



IDEA-Partnership on education by Anne Bernay

A little-known but extremely useful tool on the internet is the website of the **IDEA Partnership**. The IDEA Partnership reflects the collaborative work of 55 national organizations, technical assistance providers, and organizations and agencies at state and local levels. Together with the Office of Special Education Programs (OSEP), the Partner Organizations form a community with the potential to transform the way we work as stakeholders in the education process and to improve outcomes for students and youth with disabilities.

The IDEA Partnership uses existing networks, such as the Down syndrome national, regional and local organizations, in the hope of reaching new levels of impact from existing and ongoing research and to come together to solve complex issues. The IDEA Partnership believes that existing organizations are natural outlets for materials they develop and that when states work with the state affiliates of national organizations, ideas can change practice. These groups working together can make implementation of research-based best practices a reality.

In January 2011, Patricia Linehan, from the IDEA Partnership, shared an overview of the resources available on their website and the key areas they are focusing on during a webinar hosted by the National Down Syndrome Society.

Some of the current focus areas include Response to Intervention (RTI), School Behavioral Health, Creating Agreement / Appropriate Dispute Resolution, Universal Design for Learning (UDL), Early Childhood and P-16/20 Pipeline: Cradle to College & Career.

Ms Linehan explained that **Cradle to College & Career** is focused on promoting a lifetime of learning and expanding the notion of college for kids with intellectual disabilities. It also includes efforts to develop **Next Generation Learners** – the new skills that are needed by our children and better ways to deliver instruction and make learning more real.

School Behavioral Health, another focus area, addresses non-academic barriers to achievement. Ms Linehan also spoke about school improvements under the

Elementary and Secondary Education Act (ESEA), which pushes our kids more and more, but is also now recognized as being somewhat in conflict with our kids' natural development. This is a topic of discussion and concern that the IDEA Partnership is beginning to look at.

The IDEA Partnership website contains numerous resources helpful to parents as they navigate Special Education:

- The history and key points of various **special education laws**, such as No Child Left Behind (NCLB) and Individuals with Disabilities Education Act (IDEA)
- **LearningPort National Professional Development Library**: a library of learning modules, tool kits, archive webinars and video resources designed by OSEP for schools to use for professional development, but also useful to parents.
- **Many Voices**: called a “work in progress,” this is a collection of citations and links to selected articles from a large number of professional journals and publications available online. All are relevant to No Child Left Behind and IDEA and cover topics such as behavior, early childhood, inclusive education, mental health, instructional strategies, therapy, testing and accountability, transitions and technology.
- **Center on Instruction**: provides a cutting-edge collection of documents on research-based instruction (some are not yet available). These free resources include syntheses of recent research, practitioner guides, professional development materials, tools for educators, and examples from the field. Literacy, mathematics, science, and special education are just a few of the categories included.

Parents and professionals can sign up for the IDEA quarterly newsletter and access the resources on the website for help in understanding best practices in special education and to aid them in working with their child's educators.

Do you want to know more?

Find the **Partnership** at www.ideapartnership.org



Patricia Linehans presentation slides are available [here](#).

Find the **Library** at <http://www.learningport.us>

Find the **Center** at: www.centeroninstruction.org

Or send an email to education@clearlaked.org

Zoe in the spotlight by Amy Coykendall



Do you want to be in the spotlight with your child?

Send an email to newsletter@clearlakede.org

GCLFEDS has a brand new website! Check it out at www.clearlakede.org



Inspiration? 😊

Sometimes we're tired of the daily care with medical appointments, therapy or paperwork. We then need some inspiration to wake up with a smile the next day. GCLFEDS wants to share the thoughts on this page with you. Want to share something yourself? Email newsletter@clearlake.org

At 23 I had a 1 in 1500 chance of having a child with Down syndrome so it never crossed my mind that I would be blessed with one. But here I stand amongst such wonderful families who have been blessed just as much as I have, if not more. The way I see it is life is never how you plan it to be, so when life hands you lemonades you can either make lemonade or not. I chose to make lemonade and it is the best lemonade I've ever had!

Life with Zoe is frustrating, hard, lonely, terrifying, isolating, stressful, but it is also rewarding, an eye opener, joyous, fulfilling, interesting, educating, happy, and everything in between. I would not be able to do it by myself without the love and support from my friends and my family, especially my parents. I am currently living with my parents due to not being able to work with Zoe having so many doctor appointments and being in and out of the hospital. They help me support Zoe and are there for me when I need help, or even just a break to have a few minutes to myself. As I had never thought of having a child with special needs, I never thought I would be a single mom. Zoe's dad comes around every so often to see her.

He was there with me when I found out about her health problems and the diagnosis of Down syndrome, but he currently lives in another city.

I treat Zoe like I treat any other child her age and will continue to do so as she grows older. I do not want her growing up thinking she cannot do what others are doing just because she is different. I see her being in Kindergarten at 5, graduating high school at 18, going to college, and doing whatever she sets her mind to. I will not let Down syndrome define her but have her define her own self.



Some inspiration by Silvie Warmerdam

😊 "Never give up!!!" exclaimed Andy Noser, a self advocate and speaker at our November meeting. He gave a detailed account of his wonderful accomplishments, including getting a driver's license, working independently, and getting married. But most moving was his answer to the question on what his advice would be to parents of newborns: "Never give up!!!" Andy is the living example of his own advice.

😊 David calls Monica the love of his life. Monica smiles and gives him another hug. In the romantic documentary 'Monica and David', which premiered on HBO in October 2010, we witness the

wedding and the married life of these two people with Down syndrome. Grasp a Kleenex and watch the trailer at www.monicaanddavid.com.

😊 Johnny the bagger transformed the grocery store he worked at with his 'Thoughts of the day' and a long line was waiting to be served by him (you'll need another Kleenex): <http://www.stservicemovie.com/>



Upcoming Events

February 17 2011
Monthly Meeting

Hearing Loss and your child

By Kristi Ferguson, M.Ed, CED

Facts and Figures
Impacts of Hearing loss on Language Development
Amplification: hearing aids and cochlear implants
Communication options: sign language, spoken language, picture communication: Which fit your child's individual needs?
Questions & Answers

March 24 2011
Monthly Meeting

Your child's future

By Kimberly Hegwood

Eligibility for gov. programs
Work and SSI and SSDI
Housing options
Guardianship
Long term support system
Special needs trusts

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

6:30 pm
Pizza and informal
discussion
7:00 pm
Speakers

Child care provided:
please RSVP
meetings@clearlaked.org .
or using the website at
www.clearlaked.org

T21 Conference -continued

Cognitive Research

During lunch, the floor was given to Dr. Michael Harpold, Chief Scientist of Down Syndrome Research and Treatment Foundation (DSRTF). He gave the audience an update about the biomedical research being done since 2004. DSRTF is the same kind of organization as Research Down Syndrome. Dr. Harpold's words resonated with the words Dr. Schoen had spoken during the GCLFEDS January monthly meeting (see page 4). He emphasized that human trials were on their way. Not only because the biomedical research was ready for it, but also because on the other side of the spectrum people were ready. A databank where people with Down syndrome can sign up is being prepared. And researchers at the University of Arizona have developed a new non-verbal test to measure and prove results of the human trials: the Arizona Cognitive Test Battery (ACTB).

Independent lives

In the afternoon the mothers of Austin and Christie Hockel Davenport provided their unique stories. Judie Hockel shared her view on being Christie's mom: "You begin pushing when your child is born and you never stop." While Austin and Christi are married and lead very independent lives with a lot of opportunities, there are still real limitations and challenges that they and their parents face. Austin and Christi live in one unit of a duplex, with state caregivers in a connected unit next door.

Austin's mom, Nancy Lambert Davenport, lives nearby and visits the couple about three times a week. Because of social security benefit issues, Christi returns to California regularly. Austin is employed full-time, but there are days when he must be encouraged to go to work. Since Christi is no longer under the watchful eye of her mother, she gained weight and faces nutritional challenges.

When Austin and Christie began to get serious about each other, it was Christie who always wanted to get married, while Austin was not so sure about the idea. But eventually, Nancy said, she realized that Austin cared more about Christie's happiness and well-being than his own. She knew that Austin was in love and that maybe the idea that they could get married wasn't so crazy after all.

Do you want to know more?

Go to www.fathersjoy.org to order the DVD of the full conference and learn about all the different sessions.

The website www.powerof2.org has information about co-teaching or send an email to the speakers: lisa.kirby@esc20.net or kimberly.baumgardner@esc20.net . Read more about the cognitive research and the new cognitive test (ACTB) at www.DSRTF.org.

Pulmonary information and information about other childhood illnesses can be found at the Texas Children's Hospital website:

<http://www.texaschildrens.org/parents/tins>

The T21 organisations:





New Members

Welcome

Steve & Karye McLendon – Parker (8)
 Roy & Catherine Wilty – Powers (4)
 Kathleen Longrigg – Michelle (42)
 Sharon Harrelson – Grandmother of Austin
 Lisa Rawls –Owen (5)

Welcome back

Vince & Laura Johnson – Morgan (4)
 Chris & Alicia Dague – Anna (6)
 Harro Van de Rhee & Silvie Warmerdam – Daniel (6)
 Kileen McDonald & Pam Colwell – Ches (3)
 Joel & Heather Burdeaux – Arabella (9) & Darin (5)
 Mike & Blanka Bhrluk – Sarah (11)
 Steve & Anne Bernay – Peter (9)

We welcome articles and contributions to the newsletter. Send them to Silvie Warmerdam at newsletter@clearlakeds.org

The deadline for submissions to the April newsletter is April 5 2011

Greater Clear Lake Families Exploring Down Syndrome

E-mail
gclfeds@clearlakeds.org

Web site
www.clearlakeds.org



Thank You!

Our gratitude and thanks to the speakers, volunteers & vendors of the 2nd Annual T21 conference and to the GCLFEDS members who came out in support of the 2nd Annual T21 conference.

Thank you Alicia Dague for organizing the T21-conference on behalf of GCLFEDS.

Thank you to Life Church for allowing us to use the facilities for the GCLFEDS Board Annual Planning Meeting.

Thank you Vince Johnson for setting up the new website: it looks great!
 Thank you Tiffany Novick for organizing the wonderful winter holiday social.

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.

