



# NEWSLETTER

## Use of new blood test requires balanced information

In early 2012 there will be a new blood test for pregnant women on the market that will be able to more accurately and conclusively identify Down syndrome using a sample of blood drawn from the mother. Dr. Brian Skotko discussed the test at the 2011 Down Syndrome Affiliates In Action (DSAIA) Conference in Dallas, noting that more women will be tested and it will be even more important for medical professionals to “deliver complete, consistent, nonjudgmental, non-coercive information.”

### Research

Researchers from the University of Hong Kong have been working on a DNA-based blood test for a decade. In their largest study yet, the researchers analyzed blood samples from 753 pregnant women; the test identified every case of Down syndrome and produced only a handful of false positives. The results were published online in the British Medical Journal in February 2011.

### The blood test

The safe and relatively cheap blood test is aimed at replacing the CVS and amniocentesis tests, which are expensive tests with risks for the baby. Sequenom Inc. has licensed the technology from the University of Hong Kong

and expects to make the test available to high-risk women by early 2012. The San Diego company started its own study at the beginning of January and expects to test about 2,000 samples by the middle of the year.

### Information

“Given the safety and convenience of a blood test, it’s likely many more women would get tested for Down syndrome”, says Dr. Brian Skotko, a physician in the Down Syndrome Program at Children’s Hospital Boston, in an article in the LATimes. “Thus, many more women may face a choice about pregnancy termination.”

Speaking at the DSAIA conference in March, Dr. Skotko underscored the need for up-to-date, non-directive, accurate and balanced information for prospective parents to be able to make such a decision.

Dr Skotko explains that a consortium of medical organizations and national Down syndrome organizations has been working together to develop the information needed to do this. The group, which includes national genetics and obstetrics associations, has developed standardized practice guidelines on how to deliver a diagnosis of Down syndrome, training modules to better educate medical professionals to handle these situations, *Read more on page 9*

## Who is Vince Johnson, our new president?

“When you look at the age of GCLFEDS, it is amazing how far the group has come, I want to ensure this ongoing success,” says Vince Johnson, our new president, in an interview in which he shares information about his family, his first experiences with GCLFEDS and his ambitions for the group.

### Family

Vince and his wife Laura met and married at Texas A&M. They moved to Pearland after graduation in 2000 and have been there since.

“Laura is a Kindergarten teacher and I work in the IT department of American National Insurance”, he says.

Their daughter Madison was born in 2004 and is in first grade. Their son Morgan, who has Down syndrome, was born in 2006 and is in PPCD.

Asked about what kind of father he is, Vince answers: “I try to be very active in my children’s lives and hope I am doing a good job pushing *Read more on next page.*”

## CALENDER

### April

- 19 Monthly meeting: Dr Farber, Pulmonologist
- 28 Mom’s night out at Cullen’s

### May

- 14 Spring Social
- 19 Monthly meeting: Dr Ostermaier, Down Syndrome Clinic
- 20 4th annual GCLFEDS Golf Classic

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# Providing Support to Individuals with Down Syndrome

## Who is Vince Johnson, our new president? Cont'd



Vince with Morgan at the Walk  
October 2010

**"I BELIEVE  
GCLFEDS IS IN A  
POSITION  
WHERE WE CAN  
BEGIN OFFERING  
ADDITIONAL  
SERVICES TO  
HELP SUPPORT  
OUR  
MEMBERSHIP"**

VINCE JOHNSON



Questions? Ideas? Re-  
marks? Please send one of  
the board members an  
email.

them in the right direction. Both of my kids are probably a little too spoiled, but they both have a talent for working their dad over."

### Joining GCLFEDS

The family joined GCLFEDS in 2008, after hearing about the organization from the Down Syndrome Clinic at TCH. They were looking for an organization in their area that would allow them to make contacts and get services in their community.

At the end of 2009, both Laura and Vince decided to become more active in GCLFEDS. Laura took on the Librarian role and Vince decided to volunteer with the fundraising committees in 2010 - the Walk and the Golf tournament.

Vince explains: "Since I am not a golfer, I really just tried to help out however I could with the golf tournament, whether it was working the day of the tournament, selling raffle tickets, or getting prizes. On the Walk committee, my biggest responsibility was setting up and maintaining the Walk website." This latest activity led Vince to take on the effort to update the GCLFEDS website.

### Ambitions

Vince's is clear about his ambitions for GCLFEDS: "Anne (Bernay), Alicia (Dague), Beth (Haas) and other previous board members have done such a great job of creating a strong foundation for GCLFEDS to grow on. I believe GCLFEDS is in a posi-

tion where we can begin offering additional services to help support our membership."

Although the monthly meetings will continue to be at the forefront, Vince is excited about the new offerings, starting with the free music therapy sessions for the members. "We are also exploring education related services that can make an impact to our community and hope to be able to roll several out in 2011".

### Being President

Vince says his biggest challenge is absorbing all the information that comes with a president position. "I hope everyone truly appreciates how much Anne Bernay and the other founders put into this organization. They have built a strong foundation, which is going to make my job so much easier."

Asked about what he likes the best about his role, Vince mentioned the people serving on the board and within the membership. "It is so enjoyable to see all of the families that are dedicated to making the lives of their children and others in the Down syndrome community everything they can be."

"Working with GCLFEDS has been a rewarding experience, I want to share it! Whether it is volunteering an hour to help clean up after the Walk or to serving on the board, every action is appreciated and truly helps GCLFEDS move in the right direction. My e-mail address is [pres@clearlaked.org](mailto:pres@clearlaked.org). If you have any questions, comments, or ideas, please shoot me an e-mail."

*Silvie Warmerdam*

### Board of directors

President	Vince Johnson	<a href="mailto:pres@clearlaked.org">pres@clearlaked.org</a>	281-412-9958
Vice President	Kate Meisetschlaeger	<a href="mailto:vp@clearlaked.org">vp@clearlaked.org</a>	409-996-3015
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Director	Dr Ostermeier (medical)		
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New Parent	Cristen Reat	<a href="mailto:newparent@clearlaked.org">newparent@clearlaked.org</a>	
Newsletter	Silvie Warmerdam	<a href="mailto:newsletter@clearlaked.org">newsletter@clearlaked.org</a>	281-982-7545
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Webmaster	Vince Johnson	<a href="mailto:pres@clearlaked.org">pres@clearlaked.org</a>	281-412-9958

# Providing Support to Individuals with Down Syndrome

## Thank you Lil' Rustlers Rodeo!!!

*This was GCLFEDS second year to participate in this amazing program put on by the volunteers of the Rodeo's Special Children's Committee. Fifteen children donned cowboy and cowgirl hats to rope and ride on March 3 at Reliant Stadium.*



**"LOOK MOM,  
I'M ON A HORSE  
FOR REAL"**

KEVIN WILBURN, A 10  
YEARS OLD WANNA-BE-  
COWBOY AT HIS FIRST LIL'  
RUSTLERS



# Providing Support to Individuals with Down Syndrome

## Planning your child's future

"Do you know what will happen with your children if you don't come home tonight?" asks Kimberly Hegwood, Family Attorney, at the beginning of the evening. The people who have come to the March monthly meeting are feeling a bit uneasy. Almost nobody knows exactly what would happen with their children. Tonight, Kimberly will teach some of the basics of financial and legal planning for our special needs children.

### Future care planning

Kimberly first focuses on the need for future care planning. Will your child be self-sufficient? Does he or she only need someone checking in once in a while or does he or she need 24/7 support? Kimberly suggests that parents contemplate these 'what if' scenarios to be prepared for the worst.

### A special needs trust

The central point that Kimberly focuses on is the establishment of a special needs trust. "You can bequest money and assets to your special needs child, but these may prevent them from qualifying for essential benefits from the government," explains Kimberly. She is referring to the Supplemental Security Income (SSI) and Medicaid programs, providing the basic necessities such as food, housing and clothing.

"As you can imagine, these limited benefits will not allow your loved ones to enjoy a richer quality of life. A trust can," Kimberly continues.

The government has established rules allowing assets to be held in trust, called a "Special Needs" or "Supplemental Needs" Trust for the benefit of a

recipient of SSI and Medicaid, as long as certain requirements are met. Kimberly advises parents to get a life insurance policy to provide the money for the trust.

### Build a Team

Another focus point of the evening has to do with the people who will be responsible for your children if you won't be there to take care of them. "You probably have someone appointed as a guardian," Kimberly suggests. "But are those names still up to date? Do the people know their names are on your list?"

Your child will need a Trustee, preferably not the same person as the guardian. "For a guardian it will be tempting to use money from the trust to buy a bigger family car, although that is not the purpose of the trust," Kimberly warns. Other people in the team would be a care advocate, who speaks up for the rights of your child, an attorney to give advice, and family members.

### Message

"You have to take care of three retirement plans: for yourself, your partner and for your special needs child. If you don't do it, others will and you can't be sure they will do it the way you want life to be for your child," summarizes Kimberly.

*Silvie Warmerdam*

**"YOU HAVE TO TAKE CARE OF THREE RETIREMENT PLANS: FOR YOURSELF, YOUR PARTNER AND FOR YOUR SPECIAL NEEDS CHILD."** KIMBERLY HEGWOOD

Want to know more?

Go to [Hegwood-Law.com](http://Hegwood-Law.com) and subscribe to the email newsletter.



## Monthly meeting on the Calendar

### TUESDAY

April 19, 2011

Dr Farber, pulmonologist

Dr. Harold J. Farber will talk on Pulmonary Issues. He will cover common respiratory illnesses, how they can affect children and adults with Down syndrome more profoundly than typical kids. How to treat them at home and Why it is important to diagnose and treat sleep apnea? He'll also answer questions from parents.

Dr. Harold J. Farber is an Associate Professor of Pediatrics at Baylor College of Medicine, specializing in pediatric pulmonary medicine. He attended medical school at State University of New York at Stony Brook, did his residency at USC, Los Angeles and his fellowship at Tulane University Medical Center. Dr. Farber sees several GCLFEDS members at the Clear Lake Health Clinic and at Texas Children's Hospital.

### THURSDAY

May 19, 2011

Dr Ostermaier, Down Syndrome Clinic

Dr Kathryn Ostermaier will talk about the Down Syndrome Clinic: what it is, what to expect when you go there and the most common things the clinic will see that pediatricians have overlooked.

She will give tips how to manage common illnesses in Children with Down Syndrome, and she'll discuss medical resources.

Dr Ostermaier is medical advisor of the GCLFEDS board and Clinic Chief for the Down Syndrome Clinic at Texas Children's Hospital since 2009. She specializes in developmental pediatrics. She graduated from Texas A&M University and received her M.D. at Baylor College of Medicine .

### Monthly Meeting

6:30 dinner and dessert

7:00 presentation

United Way Building

Bay Area Blvd

Childcare provided

[RSVP here](#)

#### NOTE:

April 19 @ Clear Lake

Baptist Church,

15700 Space Ctr Blvd

# Providing Support to Individuals with Down Syndrome

## Music Therapy: free for members

GCLFEDS is offering group music therapy sessions. Sessions are free to paying members (membership fee \$25) and \$10/session to non-members.

Sessions will be held for ages 3 - 6 on the 1st and 3rd Thursday each month at 6:00-6:45 p.m. at the United Way building.

Sessions for Age 7 and up will be held the 2nd and 4th Thursday from 6:00-7:00 p.m. at the United Way Building.

At this time the 3-6 year old class is full, but we are opening a "wait list" for interested families. There are still spots available for the

7+ class and we have received interest from some adults but need more to warrant opening a class.

The Music Therapy Center of Houston provides the therapy. Look at their [website](#) for all the info about their programs.

Please note we are only able to provide these services to individuals with Down syndrome. If you are interested in participating or have questions, please e-mail [gclfeds@clearlakeds.org](mailto:gclfeds@clearlakeds.org).



"Music Therapy is an established healthcare profession that uses music to address physical, emotional, cognitive, and social needs of individuals of all ages." The American Music Therapy Association.



"I HOPE THE  
MUSIC THERAPY  
CONTINUES AS  
I THINK IT IS  
BENEFICIAL FOR  
OUR CHILDREN"

KILEEN MCDONALD, MOM  
TO CHES AGE 3.

## Music Therapy: a great idea

"My name is Kileen McDonald. My son Ches, follows the Music Therapy GCLFEDS is offering. Ches, who is in the 3-6 year old class, loves music and dancing, so I knew he would like to participate in music therapy. The first session included singing, finger puppets, playing instruments including hand drums and guitar, and playing with scarves. I am looking forward to the next session to see

what the music therapist has to offer for the kids. I think GCLFEDS offering Music Therapy for our kids is a great idea. Any therapy for our children is an essential. I hope the music therapy continues as I think it is beneficial for our children, and it's FREE. "

*Kileen McDonald*



## Providing Support to Individuals with Down Syndrome



**It's time for our annual spring social Cinco de Mayo style!!**

Please RSVP by Monday May 2nd to ensure we have enough food.

Call Tiffany 832-385-0596 or go to [www.clearlakeds.org](http://www.clearlakeds.org)

# Providing Support to Individuals with Down Syndrome

## Helping our kids manage transitions successfully

School days are filled with many different kinds of transitions. We often hear that a student acted out for “no apparent reason” but the reality is that you may have asked that student to manage more transitions than he/she could cope with. Transitions take place when students change what they are currently doing or when they move from one activity to the next.

**Macro changes:** change of staff, change of location (either in the classroom or in the school), change of subject, moving from individual work to group work, working with a different student and change of school

**Micro changes:** change of activity or expectation within a class such as changing from reading to writing, changing from writing to putting things away, changing from listening to responding to questions or telling a story. Also includes changing the pace of work, the amount of work or the materials to be used within a single lesson.

### Internal factors that affect student’s ability to transition

**Perception of the situation:** The student may perceive the change as harder, less pleasant, or less understandable. On the other hand, if the student sees the change as positive he will have less difficulty with cooperating with the change.

**Motor planning:** Students with Down syndrome tend to need more time to process requests, both at a physical and at a cognitive level. If they are rushed they may not manage transitions successfully.

**Attention/fixation on the task at hand:** Some students do not want to leave the task they are working on; especially if they are achieving success with the task.

**Attention to the next task:** Other students will rush to the next task without properly finishing up on the previous task.

**Motivation:** Some students don’t care about getting through “your” schedule, they may not understand why you are asking them to do yet another task. They may not want to cooperate because they do not understand the routine.

**History of this situation:** If a student has had difficulty in a certain class/task they may be less likely to cooperate with the transition to that task. If they have had success, the transition will be smoother.

**Communication skills:** Students with Down syndrome tend to have communication challenges that affect their ability to negotiate for more time or to ask for an explanation about why the change is happening. Often a refusal to cooperate is communicating that the transition is causing stress of some kind for the student.

**Health:** Some students may be ill and not be able to tell you something is wrong. In this case they may be less cooperative with transitions. Many students with Down syndrome suffer from Obstructive Sleep Apnea which impedes their ability to cooperate due to lack of sleep.

**Sensory challenges:** Some students who have sensory integration challenges, will have difficulty with any change as they are using all of their energy to cope with their sensory challenges. These students will have difficulty with transitions until they feel less overwhelmed within the classroom setting.

### External factors that affect student’s ability to transition

**Environment:** Many students are affected by the noise and activity level in a classroom.

**Who’s requesting the change:** Some students will respond to some people better than others; this includes all staff and peers.

**How the request is made:** If a student feels threatened or embarrassed with a request or does not understand a request, the student may not respond.

**Why the request is made:** Some requests “come out of the blue” and may not make sense to a student who is quite happy doing what he is currently doing.

**What the task looks like:** If the task “looks” hard, the student may not cooperate with the change.

**Who else is doing the task:** Most students will look around to see who else is doing the task, if he feels singled out with the task, he may resist.

To help your students it’s important you make PLANS for transitions. See the chart on page 9 for strategies which will help you minimize frustrations resulting from transitions.

*By Carol Johnson, CDSS Information Manager*

*Taken with permission from the Fall 2010 edition of Inclusion Solutions, produced by the Down Syndrome Guild of Greater Kansas City*



“THESE FACTORS  
AREN’T ONLY  
TRUE IN A  
CLASSROOM,  
BUT AT HOME  
AS WELL”

SILVIE WARMERDAM,  
NEWSLETTER EDITOR



# Providing Support to Individuals with Down Syndrome

## Some Inspiration



We all need inspiration to keep going. Enjoy these and send yours to [newsletter@clearlaked.org](mailto:newsletter@clearlaked.org)

 **The Specials** are five British housemates, filming their lives and loves. With the slogan 'This is our world and we want to share it with you,' they have put their work online in a series of episodes of 10 minutes each and have won a number of awards. Four of the five young people have Down syndrome, the fifth has

William's syndrome. They live their own lives, make their own decisions and are supported when needed. It is hilarious, funny, tear-jerking, never patronizing and above all heart-warming. Take a look at [www.the-specials.com](http://www.the-specials.com). Don't forget to click the subtitles on because of their very, very British accents.



 "Most girls dream of being a **Cheerleader**, inspiring others by promoting the spirit of the school, wearing the illustrious uniform, which clearly identifies one as belonging to something bigger than they are. This is the ultimate desire that so many teenage girls strive for, acceptance." With these words, Emily Simino starts a story about her cheer team at a high school in California.

Emily McDaniel is part of this team. Ms. Simino writes about her: "You see, Emily has the ability to soften the hardest of hearts, to recognize the very best in everyone, measuring one's value on the size of one's smile and the sound of their laugh..." Read the whole story [here](#).

 "To honor the 400,000 Americans with Down Syndrome," the NDSS started the national campaign '**My Great Story**'. People with Down syndrome or their loved ones tell their stories online about family, friends, work, dreams coming true and never giving up. The best stories are given special attention with a professional photo shoot. Take a look at the [NDSS-website](#), be inspired by the stories or write your own.



## Or be inspired by our kids



# Providing Support to Individuals with Down Syndrome

## New members & Thank you

### Welcome new members

Anthony Swapna with Josey  
Andrea Rodriguez with Martin  
Kate Meisetschlaeger  
Rick and Eloise Karlen with LoriAnna

### Welcome back renewing members

Tiffany and Kendre Philips with Trenton  
Tiffany and Steven Novick with Joseph  
Alexis and Alexei Marchenko with Savvaty  
Andrea and Bryan Leger with Andrew

### Thank you

Thank you **Clare Bernay** for organizing the Leadership Charity Drive at UHCL to collect books, stuffed animals and diapers for the GCLFEDS newborn baskets.

Thank you **Jackie Ingram** for organizing the successful Music Therapy sessions, free for members.

Thank you **Anne Bernay** for putting together the 2010 Annual Report and completing the 2010 IRS form 990 for CFC application.



Take a look at [www.clearlaked.org](http://www.clearlaked.org) for upcoming events and membership info.

## Use of new blood test requires balanced information, *cont'd from page 1*

and worked with Lettercase.org to develop gold-standard books explaining prenatal testing for parents and physicians.

### Advocacy

Lettercase.org is an organization providing prenatal information packages for parents about genetic conditions. Funding from the NDSS and the Joseph P. Kennedy Foundation, Lettercase will distribute 10,000 booklets this year to medical professionals nationwide, including 1,600 geneticists, 2,600 genetic counselors and 4,000 obstetricians. Down syndrome affiliates attending the DSAIA conference were also given the booklets and encouraged to begin distributing them to parents and medical professionals in their local area. GCLFEDS has begun this process.

Public education about the lives and value of people with Down syndrome are also important. Campaigns like 'My Great Story' from the National Down Syndrome Society or

'We are more alike than different' from the National Down Syndrome Congress show the general public the possibilities of people with Down Syndrome.

### Call to action

A call to action was made to the Down syndrome affiliates attending the DSAIA conference. Local organizations were encouraged to educate their communities, look for media opportunities to share information about Down syndrome and to continue providing local medical professionals with balanced, accurate information they can share with their patients.

As more and more pregnant women will be tested using the new blood test, it is incumbent upon the Down syndrome community to play an important role in advocating for individuals with Down syndrome and insuring expectant mothers have the balanced, accurate information they need.

*Silvie Warmerdam  
thanks to Elizabeth Pool for editing*

## Make PLANs for transitioning students, *cont'd from page 7*

### P

**Prepare** for changes in routines using visual and or verbal prompts.

**Photograph** activities and create booklets to help students "see" the schedule for the day.

**Practice** transitions such as walking to another classroom getting books from a locker.

**Provide** accommodations on time to get to next activity as needed.

### L

**List** the things a student needs to do to be successful then teach and reinforce these skills.

**Layout** the steps to complete a task in the order they are to be done

**Limit** the interruptions in a routine, watch for too many

changes in a short period of time

**Let** the student have control over one aspect of the transition (how fast, how long)"

### A

**Anticipate** what will happen in new or unstructured settings and plan accordingly

**Acknowledge** that a situation may be stressful and find ways to make it less threatening by pairing a positive experience to the new experience (listening to music on an iPod while passing through busy hallways)

**Arrange** for visits from new staff or students to take place in a familiar environment

### N

**Note** kinds and types of changes that bother a student and plan to avoid these during transition times

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Please send copy for the June-edition to [newsletter@clearlaked.org](mailto:newsletter@clearlaked.org). Deadline is June 7, 2011

*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?*

**We're on the web:**

[www.clearlaked.org](http://www.clearlaked.org)

[@org](mailto:clearlaked@clearlaked.org)

## Don't forget the Golf tournament on May 20, 2011!

The 4th Annual GCLFEDS Charity Golf Classic will be held at Southwyck Golf Club in Pearland on May 20, 2011.



Southwyck Golf Club is a links style golf course which meanders through the Silverlake Subdivision. The Champion Bermuda greens are an outstanding putting surface - called the Bent Grass of the South - providing one of the finest sets of greens in Houston public golf courses. The course plays anywhere from 5145 yards to 6914 yards.

Download the flyer and the GCLFEDS information sheet, at the [website](#) . Use the same link to register.

If you are unable to participate in the Golf Tournament but would like to make a donation to this event, please complete the [form](#). All donations \$750 and greater will be recognized on the tournament banner and website.

Or purchase a hole sign with a picture of your (grand)child. Complete the form [here](#).

*"Please encourage folks to enter the tournament. Doing so early gets it on people's calendar and usually garners more success"*  
*John Haas, Golf tournament Chair*