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DOWN SYNDROME CLINIC EVERY FRIDAY

AT CHILDREN'S MEDICAL CENTER.

CALL (214) 456-2357

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DOWN SYNDROME GUILD OF DALLAS



MISSION STATEMENT: THE DOWN SYNDROME GUILD OF DALLAS PROVIDES ACCURATE AND CURRENT INFORMATION, RESOURCES AND SUPPORT FOR PEOPLE WITH DOWN SYNDROME, THEIR FAMILIES AND THE COMMUNITY.

ARE YOU MOVING? DON'T FORGET TO PROVIDE US WITH YOUR CHANGE OF ADDRESS BY CALLING THE OFFICE OR BY E-MAIL AT DALLASDSG@SBCGLOBAL.NET.

THE PUBLICATION OF *THE DSG NEWS* IS MADE POSSIBLE BY THE GENEROSITY OF THE CHARLES H. PHIPPS FAMILY FOUNDATION.

Down Syndrome Guild Calendar of Events

February

Mom's Escape - *Visit the website for details about the August outing.*

February 17

Dads' Group Happy Hour

February 20

IEP Clinic

February 21

New Parent
Get Together

February 27

Adult Cooking Class

THE

DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

February 2010

Affiliate of the National
Down Syndrome Congress
and the National Down
Syndrome Society

A P U B L I C A T I O N O F T H E D O W N S Y N D R O M E G U I L D O F D A L L A S

Down Syndrome Guild IEP Clinic Upcoming IEPs

Saturday, February 20, 2010
Region 10 Service Center
904 Abrams Road
Richardson, TX 75081
Saturday, 10:00 am - 12:00 pm

Providing the Just Right Challenge in Handwriting

Carla R. Austin OTR has served children and their families in an occupational therapy private practice in the Dallas area for the past 25 years. She has expertise working with young people with Down Syndrome and their families. Carla will discuss writing handwriting goals that are achievable, meaningful, and measurable for the student with Down Syndrome. She will suggest methods, materials, and modifications

to carry out a program of meaningful handwriting instruction and homework for students in elementary through high school classrooms.

Saturday, March 6, 2010
10:00 am - 12:00 pm

Toilet Training- A Complete Program for Teaching Independence

Gail Wayman, M.Ed., BCBA, has been educating children with Autism Spectrum Disorders and other special needs for fifteen years. She holds a Master's degree in Special Education and is a Board Certified Behavior Analyst (BCBA). Gail worked for a number of years as a Special Education teacher and Behavior Specialist in Texas public schools, and has provided behavioral services privately as a consultant to Dallas/Ft. Worth area school districts, other service providers for children with special needs and families implementing Applied Behavior Analysis programs in their homes. In 2004, Gail opened Wayman Learning Center, a private center providing intensive individualized behavioral services for children with autism spectrum disorders.

17th Annual Inclusion Works! Conference

Feb. 10-13, 2010
Renaissance Hotel
Austin, Texas

*Learn from national and state experts on inclusive education, co-teaching, positive behavior supports, and much more.

*Meet film maker and father Dan Habib of the video "Including Samuel" and try out innovative technology in the assistive technology lab.

*Be a leader in your school district in ensuring students with disabilities are accessing/progressing in enrolled grade level curriculum.

For additional information see the Arc of Texas Website: www.thearcoftexas.org

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**GREAT WAY TO HONOR
LOVED ONES**

Club 21
is a Down Syndrome
Guild program to honor a loved
one: matching the numeral of
the important chromosome that
affects our children.

In loving memory of Carolyn

Partain Lecoche

Barbara & Richard Muller
Joanne Broadway
Carolyn S & Joe Lecoche
The Talent Management Team
David & Julie Finto
The Emison Family

In loving memory of Martin

Pfeffer, father of Becky Slakman

Keith and Minne Blackwell
Harriett & Gary Hoffman
Jack, Sherri & Abby Munn
The Drablos Family
Steven & Lynn Campbell
Stephanie & Gary Crow

***Merry Christmas to the Drake
Family***

From: Melanie Miller

***Merry Christmas Grandma &
Grandpa***

Love Nathan, Barb, Alex, & Adam

A gift to the Down Syndrome Guild to honor loved ones is a tangible way to recognize their lives, celebrate birthdays, anniversaries, graduations, new homes, or any number of occasions.

Interested in making a *Club 21* donation? Contact Becky Slakman by e-mail at dsged@sbcglobal.net or by phone at (214) 267-1374.

Reading Matters

Reading – The Importance of Vocabulary Development

submitted by: Lynn Campbell

Reading is a complex process that involves decoding patterns and understanding the words as they are read to file into the language/learning system. Letter knowledge, phonemic awareness, and sound/letter correspondence have to do with decoding the sounds. Vocabulary breadth (the number of words) has been shown to be related to phonemic awareness whereas vocabulary depth (the richness and quality of the meaning) has been shown to predict later reading comprehension. We need to make sure that we are providing opportunities for students to learn new words while ensuring the underlying meaning in a variety of contexts is present. This is important so that our students can read for meaning rather than call out words without knowing what it means in the context. With that in mind, let's take a look at an article about developing vocabulary.

The following are excerpts taken from an article entitled, "Vocabulary Development: Five Components of a Strong Program" by Jason Mosheim and published in *ADVANCE*, Vol. 19, No. 23, August 10, 2009.

Vocabulary is the basis for meaning in verbal and written communication as well as reading. In order to continually develop in these three areas, our students need specific instruction. Vocabulary affects reading comprehension because all content is conveyed through vocabulary.

According to Anita Archer, PhD, an educational consultant based in Portland, OR, there are five components of a strong vocabulary program: high-quality classroom language, reading aloud, explicit vocabulary instruction, an instructional routine for vocabulary, and word-learning strategies.

There is a tendency for teachers to

reduce the complexity of their vocabulary drastically. Dr. Archer encourages teachers to use rich language followed by explanations and examples so students are able to understand. Parents can do the same at home.

Reading aloud is critical in preschool and the primary grades because vocabulary in print material is significantly higher than it is in conversational English. It is both educational and entertaining when parents read books to preschoolers. Teachers and parents can augment their reading by changing intonation, pointing to pictures, and acting out scenes. They should request responses from the students, ask for predictions, and have them retell parts of the story. Most importantly, they should take time to explain any unknown, novel words. Children gain approximately 80 percent of their vocabulary from the explicit introduction to words, research has shown.

Students with language difficulties and struggling readers need more explicit instruction to gain vocabulary. In vocabulary instruction it is important to introduce the word and have the student say the word, give a definition, "student-friendly" explanation, and examples of what the word means and how it might be used, and then provide opportunities for the student to use the word in a meaningful context. It is important to give more than one example as struggling students or students with less language variety often attach the wrong understanding if the range of examples is narrow. This will enable the student to identify and read for meaning in another context when it shows up again.

An evidence-based approach to getting students to practice using certain words is to ask them to discern between examples.



Luke O'Brien enjoys a dance party with friends.

The Down Syndrome Guild of Dallas is very thankful to students at Cistercian Preparatory School for hosting dances for our teens and young adults twice a year.

President's Message

By Kelly Drablos

One of the most important missions of the Down Syndrome Guild is to make accurate, current information available to families of people with Down syndrome and the professionals who work with them. From there we strive to make that same information available to our community as a whole to the greatest extent possible. It is an ongoing and ever changing process requiring tenacity, patience and enthusiasm. We battle misconceptions and fears as we move forward. Progress can seem slow. We document our work to insure its permanence.

This newsletter is a critical part of that effort. Our website is as well. We paint positive images and give those pictures validity with the evidence

we gather. We seek to spread the good news that people with Down syndrome can do with supports. We describe what effective supports look like. Take comfort in the fact that this process is proceeding and become a part of sharing our resources with all who can benefit.

To that end make sure your friends and colleagues are aware of our remaining two IEP clinics this month and in March concerning handwriting and toilet training. All year we have been publishing information regarding reading. Use these tools. Be informed and inform others. More progress will occur if more of us participate. Our vision of "people with Down syndrome, valued and included" is our goal

Quarterly Get Together for Parents of Babies with Down Syndrome

Jewish Community Center of Dallas

7900 Northaven Road

Dallas, TX 75230-3392

Sunday, February 21st

3:00 pm – 5:00 pm

Meeting room: Big D Room

Sibling play room: Yad B'Yad Room

The Big D Room and Yad B'Yad Room are right next to each other. Once you walk in the front door of the J.C. Center, you go straight ahead down the main meeting room hallway and they are the first and second rooms on the right.

We realize that with the birth of your child with Down syndrome you may have entered a whole new world - one that can be confusing and filled with deep feelings at first. Please join us for our New Parent Get Together! Come meet other parents, some new and some not so new! Get information, ask questions, find out how the Down Syndrome Guild of Dallas can be a resource and support for you and your family. We look forward to meeting you and your family! For questions please call the DSG office at 214-267-1374.

Cooking Class for Adults with Down syndrome

Saturday, February 27, 2010
 10:00am-1:30pm
 Arapaho United
 Methodist Church
 1400 West Arapaho
 Richardson, TX 75080
 (Northeast corner of Coit &
 Arapaho- use the east parking lot
 entrance)

The New Year brings renewal of commitment to new beginnings and healthy choices. After the over indulging of sweets during the holidays what could be better than a healthy meal prepared with friends? Join Down Syndrome Guild member Jennifer Hood and friends for an exciting cooking class; Jennifer is a teacher at the Collin County Community College, and Central Market cooking schools, as well as a registered dietician. Participants will enjoy a cooking class filled with fun and flavor!

Because of space constraints, participation is limited. You must RSVP to Becky Slakman at 214-267-1374 or email dsged@sbcglobal.net to attend.

The Down Syndrome Guild Participates in the Community Transportation Network

by Cara Prentice

The Down Syndrome Guild is currently involved with The Community Transportation Network, a collaboration of agencies that are working to research and develop a plan to improve public transportation for people with disabilities and seniors in the Dallas area.

Project Overview

The Community Council of Greater Dallas earned a three-year New Freedom Program grant to weave together a network of public, private, nonprofit and faith-based transportation resources for people with disabilities and older adults. The goal is to expand the current system to fill gaps in service to help people with mobility challenges remain independent, healthy and connected. This three-year grant provides the opportunity for community agency representatives, public, private and nonprofit transportation providers, consumers and volunteers to work together to build a coordinated system with greater transportation options.

Vision

The vision for the project is that quality transportation options are fundamental to supporting independent, healthy and engaged lives for seniors and people with disabilities; better transportation services result when various transportation programs are successfully coordinated.

Progress toward Year One Objectives:

~Coalition is formed and outreach is ongoing.

~44 people representing 35 organizations have joined the coalition

Six focus groups have been held representing the following segments of the aging and disability communities:

~People with cognitive and intellectual disabilities and their caregivers

~People with physical disabilities

~Low- to moderate-income seniors and people with disabilities

~Seniors and people with disabilities

who have limited English proficiency

~Seniors in general

~People who are deaf or hard of hearing

~75 people with mobility needs have participated. These participants reside in 28 different zip codes; thus, we have successfully included people from various parts of Dallas County

Survey of transportation resources is underway.

The Research Committee is in the process of conducting a survey of existing transportation resources in Dallas County.

~Over 30 businesses and organizations have been asked to complete the survey

~A team of trained volunteers is working to ensure a high response rate by making reminder phone calls

~Additional resources continue to be identified. These organizations will be strongly encouraged to complete the survey by the end of the year

City of Dallas sustains Senior Medical Transportation Program.

Despite the City of Dallas budget shortfall, the City's Senior Medical Transportation Program will be funded to maintain its existing level of service for the next fiscal year

The Community Council is contracting with the City to expand the program to include people with disabilities by acquiring a wheelchair accessible van and hiring an additional driver.

The DSG is proud to be an active participant in such an important endeavor. If you have ever tried to go anywhere using public transportation or the current Dart Paratransit system, you know that there is room for improvement. We are excited about the opportunity to serve on this panel and provide input which will benefit our members and their families. Watch for more updates as the collaborative effort moves forward.

Most of the word-learning strategies in vocabulary instruction relate to reading. One strategy is to use context clues – a process adults use automatically by requires explicit instruction for younger students.

If a student doesn't know the meaning of a particular word during a unit study in school, it will significantly reduce understanding of the entire unit. Students need to have an in-depth understanding of a word and some idea of the context in which it is utilized for vocabulary to boost their reading comprehension.

The article ends with a quote by Dr. Archer – “We have this vast, beautiful language; and it is marked by vocabulary. It facilitates the acquisition of knowledge, and it is the knowledge.”

Next month's article will discuss reading comprehension and its relationship to language and cognitive development.

Dad's Group Happy Hour

Wednesday, February 17, 2010
6:30 pm - 8:30 pm
The Londoner
14930 Midway Road
Addison, TX 75001
phone: (972) 458-2444

Join co-chairs, Chris McKee and Doug Dureau, for drinks and conversation. Feel free to invite other Down Syndrome Guild dads who might enjoy attending. RSVP to Becky Slakman at (214) 267-1374 or via e-mail at dsged@sbcglobal.net. Not able to join this time, but would like to be added to the list to receive information for future events? Let Becky know that as well.

Updated Resource Guide for Families of Adults with Down Syndrome now Available

For the families of people with Down syndrome, one of the most important and challenging transitions is when our family member is no longer eligible for school services. The world of services for adults with Down syndrome is a complex maze of government and private agencies, each with its own eligibility requirements, rules, and program options. While in school, most if not all of the resources that make up a student's principle support system of special education and related services are mandated by law. Upon graduation, the student will no longer have an entitlement to many of the services. The process of acquiring appropriate services by identifying, applying for, and coordinating appropriate resources will fall mainly upon the family. In an attempt to assist our member families, the Down Syndrome Guild has updated and published the 2009 Resource Guide for Families of Adults with Down Syndrome. If you would like a copy, please contact Jessica McCartney in the DSG office at 214-267-1374 or at dallasdsg@sbcglobal.net



Dylan Diener and volunteers from National Charity League enjoy a morning of snacks and games at the DSG's annual Snackin' with Santa program.

Benefits of the DS Clinic for the Older Child

By Joanna Spahis, RN, CNS, APNG

The Down Syndrome Clinic at Children's Medical Center of Dallas has been serving the needs of children with DS since 1993. Any child from birth until age 18 years is eligible and welcome. While the clinic sees between 150-200 children with DS annually, most of these are under the age of 5 years; however, there are benefits for older children and adolescents too. Below are some examples.

Q: My daughter is nearing puberty and I'm concerned about how she will manage her periods. I would like to know what kind of help is available to her in the future.

A: Most young women with DS are able to learn to manage their own menstrual hygiene issues. Children's Medical Center has an adolescent clinic for young men and women between the ages of 11 and 18 years, to which teens can be referred. Gynecologic consultation and treatment of other adolescent concerns is offered.

Q: My teen aged son has recently started to gain weight rapidly. Is this common?

A: Excess weight gain is seen often among teens with DS around the time of adolescence. A registered dietitian, Katie Green, is available for dietary management at the time of the DS Clinic visit or by telephone. There is also a nutrition clinic available for long-term help. Another cause of rapid weight gain may be due to hypothyroidism. Thyroid levels are routinely checked during visits to the DS Clinic.

Q: Are adolescents with DS prone to depression? My daughter seems to be very quiet and not interested in her usual activities lately.

A: Certain mental changes (including depression) and behavior changes can occur in older children with DS. Debbie Clark, clinical social worker, is available to discuss these types of concerns with parents during the DS Clinic visit and make referrals to mental health professionals as needed. There is also a research effort underway at UT Southwestern Medical Center to study the brain function of adolescents with DS. Subjects are now being recruited – contact the DS Clinic for additional information.

Q: I have questions about government programs and planning for my child's

future.

A: A parent volunteer from the Down Syndrome Guild is a member of the team at the DS Clinic. She will share her personal experiences, provide handouts and connect the family to other DSG resources.

The DS Clinic at Children's Medical Center of Dallas can be helpful for various medical, psychosocial, and community issues that can affect older children and adolescents up to the age of 18 years. A follow-up letter is sent to the primary care physician after each visit with details about the findings and recommendations. If there are questions about the DS Clinic, please contact Joanna Spahis, clinical nurse specialist at 214-456-2017 or by email at Joanna.Spahis@childrens.com.

DSG Bingo



Emily Pendergrass and other self advocates brought an afternoon of bingo to the Legacy at Preston Hollow assisted living facility.

Becoming an Advocate *adapted with permission from Aaron Howard, Jewish Herald-Voice*

Colleen Horton began as an advocate for her daughter who has autism. She simply wanted to make sure her daughter got a quality education. The more Horton engaged her local school district, the more she realized that almost all kids with special needs in Texas were being short changed. Either there weren't services or parents didn't know about services. That's when Horton realized: if you want to change the system, you need to know how to analyze the problems and come up with workable solutions.

Today Colleen Horton is Public Policy Director with The Texas Center for Disability Studies at University of Texas, Austin (UT). The Center is part of a federally funded program to do public policy, community education, research and evaluation through UT. She's also active with the Disability Policy Consortium, an independent group of statewide advocacy organizations that strives to achieve the development and full implementation of public policy that promotes and supports the rights, inclusion, integration, and independence of Texans with disabilities.

Although Horton made the jump from parent advocate to professional, she emphasizes that often the parents or young people with disabilities are the best advocates. "It takes a lot of different players to make things happen," she says. "The organizational advocates who are primarily in Austin can go to committee hearings. But if Austin legislators don't hear from folks back home about an issue, we won't get their attention. The more you can collaborate, the more effective you will be." Horton believes that becoming an effective parent or self-advocate is a five-step process.

Lesson #1- You can't do it by yourself

"It's very important to partner with others who are interested in some of the same issues, especially when you're new to disability issues," she says. "It provides emotional support to be around people who are experiencing the same thing. It also empowers you with information to fight for what you need with your doctor, in the classroom and in wider issues.

Lesson #2- The more people you can join with, the better the possibility to impact the system.

Although parents tend to focus on their child, any child with autism or Down Syndrome or cerebral palsy will tend to encounter the same barriers. "Believe me, I knew nothing when I started advocacy training," said Horton. "It was an incredible puzzle to try to piece together. The key is not to get frustrated because it takes years to learn how the system works. Learn to focus your efforts. Choose what you are passionate about and focus on that.

Lesson #3- Find a mentor

You can do it by going to meetings, by getting on list serves, by speaking with other parents, and by contacting local disability organizations suggests Horton. "You need somebody you can trust, who knows the answer or who knows where to find the answer", she says. "You always want to know you're passing on good information. You don't need to reinvent the wheel. One of the benefits of having a mentor is they are able to tell you what's been tried, what hasn't worked. In short, a mentor can save you a lot of time and effort."

Lesson #4- Come up with possible solutions

Once you have people to work with and know where to get accurate information, decide what you want to work on. "Start gathering information," says Horton. "You need to do your homework first. You need to be able to say first: here's the problem. Second, here's the evidence it is a problem. You don't need scientific data. It can be anecdotal evidence. And three, present your recommendations. If you don't have solutions that you can present, then you're not to the point where you're ready to take the problem to the policy makers. That piece may scare folks. But when you're working with a group of people, you start hashing things out and it's very possible to come up with solutions.

Lesson #5- Build relationships with agencies and policymakers.

Having an ongoing relationship builds confidence in you, and that your recommendations are valid, said Horton. "In a huge school district, they might not remember you right away, it takes time" she says. "Every legislator in Austin has a local office. That's a good place to start the relationship. Make an appointment to talk about issues facing families who are raising kids with disabilities. Take some people with you. Always end a call or visit with an offer to provide more information. Or ask them to provide you with more information so immediately you have reason to follow up and have a second discussion. Keep that going over time. When trust is built up, they will call you seeking ways to solve the problem. Legislators are primarily there to address the needs of their constituents. Not nearly enough families take advantage of that."