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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

This month on the DSG Calendar, Allison and Luke know how to pass those winter days.



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

January

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

January 10

Down syndrome / Autism Interest Group

January 14

Meeting for Parents of Adults with Down syndrome

January 24

IEP Clinic – Inclusion: From Law to Implementation

THE

DSG News

PEOPLE WITH DOWN SYNDROME - VALUED AND INCLUDED

January 2009

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

Don't Miss the First IEP Clinic in 2009 *Inclusion: From Law to Implementation*

Saturday, January 24, 2009
10:00 am – 12:00 pm
Region 10 Service Center
904 Abrams Road
Richardson, TX 75081

The Down Syndrome Guild is pleased to bring to Dallas attorney *Anne Eason* and *Kathleen Whitbread, PhD*, who have designed a seminar to help parents and professionals understand the law and develop an IEP that enables students with disabilities to succeed in their neighborhood schools. Participants will walk away with ideas to create learning and social

environments that promote learning and friendship for ALL students. These presenters have co-authored a book, *IEP and Inclusion Tips for Parents and Teachers*.

This workshop is FREE for Down Syndrome Guild members and teachers! Space is limited and RSVP is required. RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.

Please see page 4 in this issue of *The DSG News* for an excerpt from their book about taping an IEP/ARD meeting.

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

*On behalf of Blake Fix, in honor
of Johann Wu's 1st Birthday*

From: The Wu Family, The Wang Family, The Ng Family, The Annabelle Yang Family, The Qi Family, The Li Family, The Lai Family, Su, Chun, Zhang, Qunshan, & Zhang Shuming, and Mitchell & Ruth Fix

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2009 Day Planners Now Available *"A Day in the Life"*

This year's calendar has a new look and style. We have a beautiful weekly planner rather than a 12 month wall calendar featuring beautiful photos of Down Syndrome Guild members of all ages. These planners will fit easily in purses and brief cases. Order several daily planners as gifts for your friends, family, teachers, and co-workers. Funds raised will support Down Syndrome Guild programs and services

but more importantly create awareness and portray a positive image of our children and adults for the community. The cost is \$15 for each planner.

To place your order, contact Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net. You can also go to our website at www.downsyndromedallas.org to download an order form and fax back to the office or mail at your convenience.

Save the Dates - February 19 & 26

Screening of *Forgotten Lives*
February 19, 2009
6:00 pm - gather
6:30 pm - screen and discuss
First Community Bank
429 Belle Grove
Richardson, TX 75080
(across the parking lot from
the DSG office)

On **February 19**, the Down Syndrome Guild will host the screening of the movie, *Forgotten Lives*. This documentary chronicles the horror and abuse perpetuated against Texas' most vulnerable citizens who live in state institutions. In response to the issues raised in this film, concerned citizens formed Community Now!, as a state-wide organization to take action to free people with disabilities from institutions.

On **February 26**, the Community Now! coalition is organizing a march and rally at the state capitol to urge legislators to provide additional support so that people with disabilities can live in the community – not institutions. Depending on level of interest, a bus may be chartered for the day trip from Dallas to Austin.

Look for more information on both these activities in the February issue of *The DSG News* or contact Becky Slakman at (214) 267-1374 or e-mail dsged@sbcglobal.net.

Executive Director's Message By Becky Slakman

Every January many of us make resolutions for the New Year. We begin with very good intentions of what we will do differently in the coming year. I challenge you to consider making one of your resolutions to be a stronger and more empowered advocate for your student with Down syndrome. Recently I read in the *Special Ed Advocate* E-newsletter (www.wrightslaw.com) an article titled the "*The 7 P's: Proper Prior Planning Prevents Pitifully Poor Performance*". This website, often referenced in articles for *The DSG News*, is an excellent resource for parents navigating their way through the special education process while ensuring that their child receives all that is entitled to him/her in an inclusive learning environment. Listed below are steps given by Jim Wright on ways to plan and prepare to be an effective advocate:

- learn new skills, strategies, techniques
- learn about your child's disability
- learn what works - effective educational practices
- learn about legal rights and responsibilities
- learn how to measure your child's educational progress
- learn about tests and measurements
- learn to negotiate and persuade

The Down Syndrome Guild's 2009 IEP Clinics, chaired by Carrie Park, offer you additional tools to advocate for your student. Our series begins on Saturday, January 24, 2009, with nationally known professionals Anne Eason, an attorney, and Kathleen Whitbread, Ph.D. who come to us from Connecticut to present "*Inclusion: From Law to Implementation*". Participants will walk away with ideas to create learning and social environments that promote

learning and friendship for ALL students. The myths of including students with disabilities in regular education classes will be examined. Attendees will see how the Individualized Education Plan (IEP) can be aligned with the general education curriculum. Regan Roth Fitzgerald, President of Behavior & Education Specialists of Texas, LLC, will speak Saturday, March 7, 2009, on Behavior Intervention Plans (BIP). Attendees will be taken through the step by step process of identifying problem behaviors and developing strategies for implementing positive intervention techniques. Our series concludes on Saturday, April 4, 2009, with Julie Liberman, owner of Speech TX, whose presentation will focus on facilitating friendships and incorporating friendship building strategies into IEP goals.

Another way to advocate for your child is to make his/her teachers aware of the educational seminars offered by the DSG. For your student to receive the best education, parents and educators must work together as a team. Invite them to attend with you. Several school districts in the area have named a *Down syndrome Specialist* to act as a liaison between the district and the DSG. *Down syndrome Specialists* receive free membership to the DSG, a monthly newsletter, a binder of current resources available for the classroom, new books on Down syndrome that pertain to learning techniques, tools for success, and information about child/adolescent development. For further information on the *Parents and Schools in Partnership*, please feel free to contact me at (214) 267-1374 or dsged@sbcglobal.net.

In closing, I hope to see you all at our upcoming IEP seminars. I wish your family a happy and healthy 2009!

In the Community

Practical Solutions for Education of Students with Down Syndrome

A workshop for parents and educators

Friday & Saturday, January 30-31, 2009

Registration at 8:30 am

Workshop from 9:00 am - 12:00 noon

Dee Kelly Center on the TCU Campus

2820 Stadium Drive

Fort Worth, TX 76129

The Down Syndrome Partnership of Tarrant County is pleased to offer the *Practical Solutions Workshop* to help you understand how to successfully engage, instruct, and enjoy your students with Down syndrome. The Friday session will be directed toward educators while the Saturday session will be directed toward parents. Both workshops are open to educators, parents, service providers, and other interested parties. A variety of topics relevant for preschoolers through young adults will be covered, including: behavioral supports, communication issues, parent/school relations, health issues, and available community resources.

There is no cost to attend but registration is required. To register, please call (817) 496-5100 or e-mail greenoaksschool@sbcglobal.net.

Blazing the Trail with Transition - 2009 Annual Texas Transition Conference

February 23-25, 2009

Doubletree Hotel

Austin, Texas

The Texas Transition Conference is an annual three-day conference that equips individuals with transition information in the hopes of improving outcomes for postsecondary opportunities for youth with disabilities. Key note speakers are internationally recognized experts with topics including: *Transitioning to the University, Student-Directed IEP Meetings, and the State of Transition in Texas* among others. For more

information contact Cheryl Grenwelge, TTC Coordinator - (979) 458-1593 or see the TTC website at <http://ttc.tamu.edu/>.

Disability Expo

February 7, 2009

1:00 pm - 4:00 pm

Garland Special Events Center

Sponsored by the Arc of Dallas in cooperation with several area school districts, this annual event brings together agencies and service providers for children and adults with cognitive disabilities. For additional information call the Arc of Dallas at (214) 634-9810.

Inclusion Works! Conference

February 25-28, 2009

Renaissance Hotel

Austin, Texas

Sponsored by the Arc of Texas, this annual state-wide meeting for parents and educators.. Many nationally-renowned experts will give presentations about "best practices" for including students with disabilities in general education classes. To register go to www.thearcoftexas.org/conferences.

Richland College Classes for Students with Down syndrome

The DSG *Options for Adults Committee* continues to network and coordinate with Richland College and The Department of Assistive and Rehabilitative Services (DARS). As a result of those efforts, we are pleased to announce the employability course offerings will be offered again in the spring 2009 semester. Registration is not available through the Richland website. For information about the classes and the registration process, families should contact Melinda Weaver at Richland at (972) 238-3750. For more information, go to www.downsyndromedallas.org.

Resource Guide for the Families of Adults with Down syndrome

To assist our member families, the Down Syndrome Guild's *Options for Adults Committee* has prepared "Resource Guide for the Families of Adults with Down Syndrome." Many of the resources are specific to the Dallas area and were identified through networking with our families. Upon reviewing this binder of information, DSG member Cinde Rawn sent the following email to Executive Director Becky Slakman:

I wanted to pass on my gratitude for the notebook on adult issues that was passed out at the Halloween dance. I can say with all honesty that it is the single most helpful collection of information we have received in Ian's twenty six years. The binder is so comprehensive, and to have so much information organized in one place is an incredible feat and a great gift to parents. I used it at the doctor's office yesterday during Ian's yearly physical. My thanks to you, to the DSG, and to those who clearly worked so hard to get it all together!

To request a copy of the Resource Guide (in a binder), please contact the DSG office by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net. A copy can also be downloaded by going to the link on the home page at www.downsyndromedallas.org.

Options for Adults - Quarterly Meeting for Parents

Wednesday,
January 14, 2009
6:00 pm - snacks
and visiting

6:30 pm - program begins

First Community Bank

429 Belle Grove

Richardson, 75080

(across the parking lot from
the DSG office)

The Down Syndrome Guild's Options for Adults Committee invites you to join us for an informative evening with Dr. Nilesh Davé, Medical Director of The Sleep and Breathing Disorders Center at UT Southwestern Medical Center. Attend this session to find out more information **about sleep apnea in adults with Down syndrome, including causes, symptoms, and treatments available.** RSVP to Becky Slakman at dsged@sbcglobal.net or (214) 267-1374.

Note: For additional information about sleep apnea in adults with DS, see the article in our December newsletter, posted at www.downsyndromedallas.org.

Pete Sessions Presents Donation to DSG



▲ Thank you to Congressman Pete Sessions, 32nd District of Texas, for suggesting that the Down Syndrome Guild be a beneficiary of fundraising efforts of the Washington DC organization, Taste of the Southwest. On October 14, 2008, Representative Sessions, who is a member of the DSG, presented a check for \$8300 to DSG President, Kelly Drablos.

Snackin' With Santa



▲ There were no dull moments at our Snackin' with Santa event.

Upcoming IEP Clinics

These workshops are designed to provide families with information to be prepared for the annual Individualized Education Plan (IEP) meeting required by school districts for every child who receives special education services. These workshops are **FREE** for Down Syndrome Guild of Dallas members and teachers! Space is limited and **RSVP is required** – (214) 267-1374 or dsged@sbcglobal.net.

Behavior Intervention Plans

Saturday, March 7, 2009

10:00 am - 12:00 pm

Region 10 Service Center

904 Abrams Road

Richardson, TX 75081

Regan Roth Fitzgerald

(M. Ed. BCBA & President Behavior & Education Specialists of Texas, LLC) will speak on how to develop and implement an effective Behavior Intervention Plan (BIP). Attendees will learn about the four main functions of all behaviors and how this relates to the development of all parts of the BIP from

the functional assessment to positive intervention strategies. The speaker will take attendees step by step through the process and have a chance to practice writing techniques and strategies for problem behaviors.

It's fun to have fun, but you have to know how!

Saturday, April 4, 2009

10:00 am - 12:00 pm

Region 10 Service Center

904 Abrams Road

Richardson, TX 75081

Julie Liberman (M.A.CCC-SLP and owner of Speech TX) will present strategies for facilitating friendships. Topics will include:

- Importance of play
- Typical development of play skills
- Different theories for teaching how to play and improve social skills
- Incorporating these skills into IEP goals and objectives

Cooking Class for Adults with Down syndrome

Saturday, January 24, 2009

10:00 am - 1:00 pm

Arapaho United

Methodist Church

1400 West Arapaho

Richardson, TX 75080

(Northeast corner of Coit & Arapaho - use the east parking lot entrance)

Winter is the perfect season to enjoy some good old fashioned home baking. It's cold outside, the house is closed up, and the wonderful smells of the season permeate through the air. Join DSG 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 tantalizing baked goodies sure to warm the heart and soul.

Because of space constraints, participation will be limited to the first 25 people to sign up. RSVP to Becky Slakman at (214) 267-1374 or e-mail dsged@sbcglobal.net.

SMU Best Buddies Wraps It Up



◀ Young adults from the DSG and the SMU Best Buddies finished out 2008 by wrapping about 500 gifts for the home-bound clients of the North Texas Visiting Nurse Association. While doing this community service project, the group had a great time together - and ate many pizzas!

IEP Tips: Taping Meetings

When you tape an IEP meeting, you have a completely accurate record of the meeting, and you will be free to listen and participate in the meeting rather than writing notes. This article includes tips about taping as well as what to do if you encounter resistance from school administrators.

Let the school know ahead of time that you will be taping. Most schools will want to have their own tape recorder running too, so this gives them notice that they will need to have a recorder and tapes.

Get a tote bag to hold your tape recorder with fresh batteries. Bring extra batteries and extra tapes. The tape packages should already be open so you are not fumbling around trying to get the wrapper off.

Mark the labels ahead of time. Otherwise, you may tape over an earlier tape. Mark the labels "Ivy Smith's IEP, date, tape one of ____."

Bring an extra tape recorder. I have seen meetings stopped because the school could not find a tape recorder. Do not rely on a power cord - there may not

be an empty outlet. Or, the cord might be too short. You don't want to create a distraction by using a big extension cord.

Use a regular sized cassette recorder, not a microcassette recorder. Small microcassettes do not produce the same quality sound and they are not as sensitive as full size cassette tapes.

Don't buy low end blank tapes. Cheap tapes stretch more easily, especially when they are in fast forward or rewind.

Make sure that your recorder makes a sound when it shuts off. You don't want to have the tape stop in the middle of the meeting, nor do you want to watch the clock to guess how much more time you have.

Buy the longest playing tapes to avoid having to switch often. Also consider bringing someone to the meeting who will watch the tape and turn it to the other side when necessary. You may easily forget to do this.

Make sure the recorder has a good microphone - one with an external mike is usually best. If you choose a tape recorder with a built-in microphone, there may be too much noise (rumbling

sound) transmitted from the motor, which drives the cassette to the microphone.

Understand how the microphone works. Point the external mike towards the ceiling, so it will pick up sounds from all around the room. If the mike is self-powered, make sure the battery is fresh.

Don't keep the tape recorder next to you. Put the recorder in the middle of the table, on a book or pad. (The motor often creates a slight rumbling that can affect the sound quality).

When the meeting is over, do not turn the tape recorder off. Keep it running. Critical information is often discussed after the official IEP meeting is over.

Listen to the tape! You'll be surprised at how much you missed during the meeting! When you get home, break the tabs to prevent anyone from taping over the tape.

Note: These tips are from the book *IEP and Inclusion Tips for Parents and Teachers* by special education attorney Anne Eason and Dr. Kathy Whitbread, who are the presenters at the DSG's IEP Clinic on January 24, 2009.

Helpful Hint Regarding Medical Coverage

For families who have private health insurance, many policies allow you to 'grandfather' in your child with a disability. Often this is effective until the parent-policy-holder's death. Some grandfathered policies also include vision and dental. This allows you a much wider base of physicians, specialists, and dentists to choose from. (Many, many specialist physicians won't accept a patient who only has Medicaid because of the low reimbursement rates.)

Here is What You Need to Know:

You must apply for this grandfathering BEFORE the cut-off date on the policy, be it age 18, age 21, etc. If your child has passed this birthday and has been dropped off your health policy, you cannot reverse this, and so there will be NO extension. Call your insurer and obtain the paperwork and get it in before this important birthday!

If your child is over age 21 and on a Medicaid-waiver program (HCS

or CLASS) and needs some dental visits, they can be provided through your child's annual "budget," calling it an adaptive aid. In some cases, transportation costs can also be included as part of the budget. This is especially important to families who live where there is no paratransit service.

New Year May Inspire Resolutions *By Nancy Davenport*

The New Year is here and some of us may be inspired to make resolutions. I have helped you out by giving you my top 10 parenting resolves. They are not necessarily mine personally. I have gleaned these from conversations with parents, children, and grandparents, articles in the paper from news to Ann Landers, and a few of my own favorites. Maybe it will help you turn over a relationship leaf with your child this year. It's never too late. Here they are:

10. I will read with my child once a day. Children are never too old for this or never too young. The benefits are dual. Not only will it help reading skills, but we are giving our child undivided attention. *Hint: turn off the TV.*

9. I will not take my child too seriously. We tend to do this especially with first-borns, especially dads. Lighten up a little. Laugh with your child.

8. By the same token, I will definitely take my child seriously. Nothing is

more devaluing than condescension.

7. I will allow my child to fail. Too often we consider any failure which our child experiences is also our failure. Get a grip. We learned 10 times more dealing with our own failures than our successes, so why deprive a child of that learning experience.

6. I will also allow my child to take risks. What better time to learn about healthy risk-taking than when parents are there as a safety net.

5. I will clear the house of junk food and fill it with good stuff. We all know how much we need good food, so just stop buying the bad. Keep treats truly treats, not as a staple. Go out for treats. Make it a family thing.

4. I will find some form of aerobic, noncompetitive exercise that my child and I can do together three times a week for 30 minutes. Good habits started now will last a lifetime. And think of that quantity of quality time.

3. With my child once a week, I will help someone else. This used to be

called doing a good deed. This doesn't have to be big things. What a great opportunity for your child to become aware of the needs of others and to focus less on him or herself. Occasionally show your child the pleasure of doing something anonymously.

2. I will encourage my child to write down his or her thoughts once a week. Some kids may be encouraged to do this if given a pretty journal with blank lined pages. Others may enjoy having a specific file on the computer for this.

1. I will pray with my child daily. To learn to turn to God first rather than as a last resort is the greatest thing you can teach a child of any ability level. You can create opportunities for good conversation with God which include listening.

I hope this little list serves to help you start your New Year with your child on good footing. Happy New Year!

Nancy Davenport is editor of "The DSG News" and can be reached at nancdave@swbell.net.

Dual Diagnosis of Down syndrome/Autism Interest Group

Saturday, January 10, 2009

10:00 am - noon

First Community Bank

429 Belle Grove

Richardson, TX 75080

(across the parking lot from the DSG office)

Please, no children

Join parent, Kathy Point, for coffee to explore the possibility of an interest group for families of children with a suspected or diagnosed combination of Down syndrome and autism. At a recent DSG Moms' Escape get-together and later via e-mail Kathy told the Down

Syndrome Guild of Dallas:

For a long time we thought our son, Preston just had DS and his behaviors were "typical" of a child with DS. We were very wrong! I recently heard that 11% of children that are born with DS also have autism. Within the last two years, I have learned a TON about autism. Through therapy, medication, supplements, and the wisdom of some very knowledgeable moms, I feel we have improved Preston's quality of life. My husband and I have a better appreciation and understanding of his behaviors and have found lots of coping skills when

his behaviors become inappropriate or unbearable.

My hope is to identify other families in the area who are struggling and need more information and education about their children's needs, especially if they are experiencing "non-typical" behavior and do not know what to do.

Parents of children with Down syndrome of any age are encouraged to attend. RSVP to Becky Slakman by phone at (214) 267-1374 or by e-mail at dsged@sbcglobal.net.