



DOWN SYNDROME ASSOCIATION  
*of Houston*

# DSAHO TODAY

October / Fall Edition 2011

## October is Down Syndrome Awareness Month Celebrate Life With Down Syndrome

THE DOWN SYNDROME ASSOCIATION OF HOUSTON'S MISSION IS TO CREATE AWARENESS AND ACCEPTANCE OF CHILDREN AND ADULTS WITH DOWN SYNDROME THROUGH ADVOCACY, SOCIALIZATION, EDUCATION AND MEDICAL OUTREACH.

WE ENVISION A WORLD IN WHICH ALL PEOPLE WITH DOWN SYNDROME HAVE THE OPPORTUNITY TO ENHANCE THEIR QUALITY OF LIFE, REALIZE THEIR LIFE ASPIRATIONS, AND BECOME ACCEPTED AS A WONDERFULLY NORMAL PART OF A VERY DIVERSE COMMUNITY.

October is National Down Syndrome Awareness Month. This is the perfect chance for you to take a few moments and educate others on what Down syndrome is and how loving someone with Down syndrome has impacted your life. The DSAH hopes you will consider some of the following activities when you are thinking about celebrating Down Syndrome Awareness Month.

- Write a letter to a local newspaper about what you have learned from people with Down syndrome.
- Take photos of your loved one with Down syndrome and send them to the DSAH for use in our promotional materials.
- Host a presentation on Down syndrome at your school, church or civic organization.
- Encourage your school to start a circle of friends program that invites typical peers to form a support network for students with Down syndrome or other disabilities.
- Thank your teachers for all that they do to help your loved one and give them a Down Syndrome Awareness Packet. For example, DS Angel's bracelets, marketing fliers, DSAH materials, DS bumper stickers. Call the DSAH if you need ideas of what to put in the packet.
- Ask a local business to donate a portion of the proceeds of their sales to the DSAH during a day or weekend of sales in October to promote awareness.

***DSAHO would love to hear any ideas you have or any successful experiences if you try some of the awareness projects listed above!***

NON-PROFIT ORG.  
U.S. POSTAGE  
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PERMIT NO. 207  
HUMBLE, TEXAS

Down Syndrome  
Association of Houston Inc.  
7015 West Tidwell  
Bldg G, Ste. #108  
Houston, Texas 77092  
www.dsaoh.org  
713-682-7237

### President's Corner

Hello Members and Friends,

October is Down Syndrome Awareness Month! Let's take a look at where DSAH has been, where we are, and where we hope to go!

Our group was incorporated in 1974 & met in the homes of members. We worked on changing words, from "mongoloid" to "Down syndrome," & educating people about DS. Laws were changed to have Special Education in schools & doctors began to talk about keeping a baby at home rather than go to a state institution.

In 1991, monthly meetings started on Thursday nights at the Multi-Service Center on West Gray. Education for our children talked about "mainstreaming" & medical advances were repairing heart problems. Some families received prenatal diagnosis of DS. In January 2008, the DS Resource Center opened & monthly meetings were moved to Saturday (in English/Spanish). More programs & services were offered & our first part-time staff hired. "Inclusion" was used in education.

Through our first two Galas in 2007/2008, money was raised to open the DS Clinic at Texas Children's Hospital serving children birth-18 years old. Our first Executive Director was hired in June 2009. In September 2009, the adult Education for Life (E4L) Program began through a \$35,000 grant from the Baxter-Trust Foundation. In 2011, E4L expanded to 24 students 2 days/week & the Pantomime Troupe performed for the public!

DSAH currently serves over 1500 families throughout Greater Houston. We collaborate with other nonprofits & offer more programs & services than ever before. Baby baskets are brought to newborns in hospitals and progress continues in education. Advocacy is local, state-wide, and national.

We have made tremendous strides for people with DS & we have so much more in store! I invite each of you to be part of the positive changes and growth for our group. We need to create the world which accepts our loved ones with DS and where they can reach their potential. We each need to do our part. Please volunteer to make progress possible.

Have a great October! See you at the Golf Tournament & Gathering of Friends!

**Ann Fontenot** SLP  
DSAH President

### DSAH OCTOBER MONTHLY MEETING

**Saturday, October 22, 2011**

**10:00 am and 1:00 pm**

**Speaker: Mr. John Pugh, MA, BCBA**

#### BEHAVIOR TLC

Applied Behavior Analysis (ABA) is the science of behavior and learning, implemented in an individual's natural environment. Behavior change and learning occur by adjusting variables in an individual's environment to promote and maintain the desirable behaviors.

One of the major strengths of ABA comes from the use of detailed data collection and data analysis. Behavioral data provide proof that behavior change and learning can be attributed to the intervention strategies being used and not due to other unknown variables.

ABA can be incredibly effective for any individual when the procedures/treatments used are implemented consistently throughout the individual's entire day. The most effective use of ABA will occur when the principles of ABA become a part of an individual's daily life. When ABA becomes a way of living and dealing with all behavior, as opposed to a type of therapy that occurs for a few hours a week, learning and behavior become most efficient and optimal.

John Pugh is a board certified behavior analyst (BCBA). He received a bachelor of science in Psychology from Missouri Southern State University and a master of arts in Behavior Analysis from the University of Houston-Clear Lake. John has also received specific training in the treatment of severe behavior disorders from the Munroe-Meyer Institute at the University of Nebraska Medical Center.

John's experience has included day and residential summer camps for children and adults with disabilities, providing in home behavior training to children and their families, providing behavior analysis services in clinical settings, conducting workshops on topics relevant to behavior analysis, and providing behavior analytic services to several school districts. John's goal for the future is continue to provide quality applied behavior analysis in homes, schools and the community.

You don't want to miss this! We look forward to seeing you at the meeting.

**Paula Davis**, Vice President

DSAH is now accepting applications for Board Members to serve on the board Jan 2012.

If you are interested please request an application from [info@dsah.org](mailto:info@dsah.org).

#### LOST 'n FOUND:

Several years back, DSAH loaned someone its copy of the Circles Program. It consisted of several VHS tapes. Whoever that was, please return the tapes. Thanks!



## 2011 DOWN SYNDROME MEDICAL INTEREST GROUP MEETING AND CLINICAL SYMPOSIUM REPORT

from *Sherry Sellers Vinson, MD, MEd of The Meyer Center @ TCH*

Dr. Katie Ostermaier, chief of The Down Syndrome Clinic of Houston housed in The Meyer Center for Developmental Pediatrics at Texas Children's Hospital, and I attended the annual Down Syndrome Medical Interest Group (DSMIG) Meeting and Clinical Symposium on August 5, 2011 at the JW Marriott San Antonio Hill Country Resort & Spa held in conjunction with the August 5-7 National Down Syndrome Congress 39<sup>th</sup> Annual Convention. The DSMIG meeting included physicians, therapists, psychologists, nurses, nurse practitioners, physician assistants, and special educators connected with medical clinics serving individuals with Down Syndrome (DS). This year the meeting was attended by 52 individuals (most from across the U.S. but one each from Canada, Argentina, and Mexico), including Dr. Niru Madduri, former chief of The D.S. Clinic of Houston, who now sees individuals with D.S. in a clinic at Vanderbilt School of Medicine in Nashville, Tennessee. (Dr. Madduri is doing well, looks great, still wears her stylish outfits and shoes, and says "hello" to all in Houston.)

The meeting began at 1 p.m. and ended at 9 p.m. with only a one-hour dinner break from 6-7 p.m. with dinner being served in the meeting room so that all attendees could "talk shop" and "network". Dr. George Capone, chief of The D. S. Clinic at Kennedy Krieger Institute/Johns Hopkins School of Medicine in Baltimore, and Dr. Kim McConnell from The D.S. Clinic at Gillette Children's Hospital in St. Paul, Minnesota, organized the meeting which actually gave credits for continuing medical education to the meeting attendees for the first time. The fact that credits for continuing medical education were given indicates that the presentations were of high quality since the continuing medical education approval boards do not allow such credits unless the presentations are scrutinized beforehand by the approval boards and deemed to be appropriate for awarding credits.

The agenda for the DSMIG meeting included the following: "Review of the American Academy of Pediatrics Health Supervision Guidelines for Children with DS" (updated guideline released 7/29/11) presented by Maria Stanley, MD;"Musculoskeletal Issues in Adults with DS" presented by Siegfried Pueschel, MD;"The Adult with DS: Medical Problems, Mental Health, Cognition, Employment, and Life" presented by Nancy Roizen, MD;"Clinical Research Update regarding DS Growth Charts (presented by Mary Pipan, MD), Dynamic Computational Model of the Airway in Children with DS (presented by Sally Shott, MD), DS Patient Registry (Brian Skotko, MD), DS Clinical Research Projects Update (presented by George Capone);"International DS Projects" presented by Phil Matteis, MD;"Adult Health Care Issues Workgroup Project Overview" presented by George Capone, Peter Bulova, and David Smith, all MDs;"DS Clinics Panel" presented by representatives from DS Clinics in Maryland, Illinois, Wisconsin, and Pennsylvania. Each session's question/answer period allowed for lively discussion as did time set aside for planning the 2012 DSMIG annual meeting agenda.

Overall, I learned a lot from this meeting. I saw that most DS Clinics are interdisciplinary and have long wait lists like the one in Houston. I learned that everyone is looking for ways to improve services while reducing the wait time for clinic visits; adults with DS are living as long as the non-affected population now that health risks are better addressed than previously; we need to monitor our adults with DS to ensure their mental health needs are addressed; due to adults with DS living longer, there is limited evidence-based information regarding adult health care issues specific to DS and thus the DSMIG Adult Health Care Issues Workgroup is reviewing the literature to determine known information and to determine information needing formal study; adults with DS seem to show more symptoms indicating spine degeneration at C5-6/C6-7 and thus adult physicians should look for and address these symptoms immediately while efforts toward ensuring good bone health with exercise and intake of recommended daily vitamin D/calcium for age should begin in early childhood. Most importantly, I saw that the newly released AAP Health Supervision Guidelines are not as controversial as I had heard in that while it is true that due to current evidence not supporting performing routine screening radiographs for assessment of potential atlantoaxial instability in asymptomatic children, the recommendation for routine radiography in everyone with DS has been dropped, the recommendations for the questions to ask and physical findings for which to look for symptoms of atlantoaxial instability are more clear and thus primary care providers are less likely to miss someone who is symptomatic and thus really should have radiography.

Accordingly, all of the new AAP Guidelines give improved specific guidance to practitioners with regard to looking for feeding problems, sleep apnea, endocrine problems, hearing and vision problems, and giving the initial diagnosis of DS along with the recommendation that a chromosome karyotype should be done for everyone whose DS is evident from observation. In addition, these new guidelines explain the reason the current DS Growth Charts should not be used (these miss obesity) but advises to use the regular pediatric growth charts looking at each child's Body Mass Index until new evidence-based DS growth charts (development is in progress) are available.

### Buddy Walk 2011

Hello Buddy Walk Team Captains!



The time is almost here! Only two more months to go to celebrate our **11th Annual Houston Buddy Walk presented by our friends at Tricon Energy!!**

Something amazing has happened this year, for the first time, our Buddy Walk has a **presenting sponsor!** Tricon Energy has graciously become a **Platinum Sponsor donating \$10,000 in honor of Allison Cañas.** We extend our most sincere thanks to Tricon Energy, its employees and **Elva Villafuerte the team captain** (and Allison's mom) who made this donation possible.

October is a very busy month for our Buddy Walk Committee. We have several deadlines that we need to keep in mind to ensure a successful event.

**October 28—ITP Questioners are due!** Please send your Imagine the PossAbilities to Cindi Condron no later than this day. Email them at [imagine@dsah.org](mailto:imagine@dsah.org)

**October 28—Last day for Sponsors to get on the back of the T-shirts!** Please submit all sponsor forms no later than this day to make sure your sponsor gets all the benefits listed. Forms and logos should be e-mailed to [buddywalk@dsah.org](mailto:buddywalk@dsah.org)

Remember to put all of your walkers on your team no later than November 5th so we can order your shirt! This year, our shirt colors will be **purple for walkers, yellow for individuals with DS and red for volunteers.**

We only have October's Team Captain meeting left on 10/13, if you are new to the BW or just have questions or don't know how to form your team, we can help you at this meeting.

Thanks to all of the supporters that have donated until now, they will really help us make a huge difference in our community! To register your team, donate, walk or register as a volunteer, please log on to [www.houstonbuddywalk.org](http://www.houstonbuddywalk.org)



Condron Family, THANK YOU for all of your hard work and dedication to the Buddy Walk. In memory of Gracie and Ally

**Alejandra Lima**  
2011 Buddy Walk Director



## 22nd Annual Gathering of Friends Festival

Invite all of your family and friends to join us as we celebrate our 22nd Annual "Gathering of Friends." We will have games, contests, food and door prizes!!

It will truly be a special day to make new friends, visit with old ones and have a GREAT TIME!

**Sunday, October 30th, 2011**  
**12:00—5:00 pm**  
**Christa V. Avair Park**  
**15107 Cullen Boulevard, Houston, Texas 77047**

### Member Needs Support

One of our member's daughter, age 11 has been recently diagnosed with hyperthyroidism. Her radiation treatment has begun and mom would like to talk to other parents in the same situation. Please contact mom at [mgonzalez6211@yahoo.com](mailto:mgonzalez6211@yahoo.com) if you could help.

### Club 21 Members

Please join us on Saturday  
**October 15th**  
at the Resource Center  
**6:00—9:00 pm**  
for our 2nd annual

**Teen/Adult**  
**Halloween Costume Party**



Space is limited; so this event is only open to Club 21 members who RSVP by Oct 11th to 713.682.7237. Remember to bring your membership card.

### Organization Seeks Siblings of People with Developmental Disabilities

Are you or do you know a sibling of a person with developmental disabilities? An organization has recently formed to improve the lives of individuals with developmental disabilities by supporting and empowering siblings and others through support, education and advocacy. If your answer is yes, please visit the SIBscape website at [www.sibscape.org](http://www.sibscape.org) or contact Stacey Mather at [stacey@sibscape.org](mailto:stacey@sibscape.org).

Dionysus' Bully Show at NDSC Available to Schools

During the first weekend in August, Dionysus Theatre headed to San Antonio to perform True Confessions of a Bully for the National Down Syndrome Conference. On Saturday, August 5 the troupe performed this original show for 80 siblings of children and youth with Down Syndrome. The powerful performance about cyber bullying, name calling, and physical aggression had an emotional impact on the young audience. During the talk back session with the cast, a high school student began to cry as she recounted her own experience involving bullies and her younger brother.

The Sunday performance took place in the Grand Ballroom of the J.W. Marriott Resort in front of the conference's general assembly. The enthusiastic audience of 1,000 leapt to their feet at the end of the show expressing their enthusiastic appreciation for Dionysus and our mission of inclusion.

The performance at the National Down Syndrome Conference was generously underwritten by the Aubrey and Sylvia Farb Community Service Fund.

The cast of six is looking forward to performing the show for middle school and high school students this coming academic year.

The Cast, Crew, and Friends of True Confessions of a Bully (Cristino Sosa, LaKeicha Thomas, Raymond Deeb, Michael Escamilla, Natalia Borja, Kelly White, Michael Iovine, and Deb Nowinski)

For information about booking the Bully Show for your school or organization, call the Dionysus offices at 713.728.0041



Saturday Respite at DSAH is Now Open to ALL Disabilities

Our new Saturday Respite Program at the Down Syndrome Association of Houston will now be accepting children with ALL disabilities ages 6 to 14. Our NEW program will focus on working with the participants on their fine and gross motor skills through various activities such as painting, arts and craft making. Our experienced personnel will be on hand to work with the participants in group settings to help them build life and social skills.

When: the second Saturday of the month

Oct 8, Nov 12, Dec 10

Time: 10:00am to 4:00pm

Where: 7015 W. Tidwell, Bldg G Suite 108, Houston, TX 77092

Price: \$30.00 per participant .To reserve your spot in our Saturday Respite Program, please call 713.682.7237 or send us an email to info@dsah.org with the participant's name, disability and parent's contact information. Due to facility restrictions, we are unable to accommodate children who use wheelchairs or medically-fragile participants.

PEDIATRICS  
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS  
**Clinical Report--Health Supervision for Children with Down Syndrome**  
Marilyn J. Bull and the COMMITTEE ON GENETICS  
*Pediatrics*; originally published online July 25, 2011;  
DOI: 10.1542/peds.2011-1605  
The online version of this article, along with updated information & services, is located on the World Wide Web at:  
<http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605>

*Tell Me How You Really Feel (Part 1)*

**Thoughts, hopes and dreams of a mother of two wonderfully wonderful girls Gabby and Andrea and the Little Hunk of Love, Ethan—who happens to have Down syndrome.**

**A blog post by Erika Marquez-Saldaña**



The last post that I wrote... it wasn't supposed to have ended the way that it did. There was more I wanted to say as to why I haven't been blogging as much but I just couldn't get it out. And its just been boiling up inside of me.

One of the reasons I do not post much is because sometimes I don't have the same feelings as other parents with children with Ds around Ethan's age. (I have found as your child gets older, your feelings shift as you get to experience different things in your journey.) But I am just getting to those other phases a little sooner than other parents. NO, I am not saying everyone will feel the way I feel when their kids are older. We all have different feelings and views on our children, Down syndrome or NOT.

I am an aggressive parent. A no nonsense type of parent. I expect A LOT from my children. I believe in tough love and yes my children better have a reason to cry about if they are crying. That is just me so naturally I am not any more different with raising Ethan. I expect a lot out of him as well, so screw you Down syndrome because I am not cutting Ethan any slack! Ok I am lying, he does tend to get babied just a tad more than his sisters were at his age, but he is too darn cute. I cave more than I like to admit, BUT I am still pretty aggressive when it comes to parenting and Ds.

And if you know me personally, you would know how much I love my son. Not only my son, but all children and adults with Ds. I am passionate for the Ds community. I try to support not only the babies and small children, but the adults as well. It is very important for me to support other adults. One day Ethan will be an adult, and I hope others will reach out to support him in whatever he does as well. I can't expect others to do that unless I am doing the same for other people's children.



Back in June I attended a fundraiser night to watch our young adults in our Ds association performing some pantomime acts to Michael Jackson songs. The acts were phenomenal, but the lack of support (from the Ds community) was bothersome. The only other people who attended were other parents of the individuals performing. Everyone seems to get excited when they see a character with Ds on TV or a child in a magazine with Ds, but when actual events are going

on in your own town and you have the opportunity to support these individuals from your very own town, no one bothers to show up, is nothing short of bothersome. (hard to take a good pic from afar and in the dark... but they were awesome! Standing ovation from the crowd!)

Recently I put together a fundraiser shopping event with an online store that sells Ds awareness items... it was a 6 week thing! They then donated 15% of the sales back to our local organization... Do you know how much money we made?... **\$23.** They had 3 sales in those 6 weeks that benefited our organization. An organization with over 1000 people, only 3 people made a purchase. One of those people was me. And I know firsthand how popular this online store is. I have friends buying from there at all times, yet in 6 weeks, I could only get 2 other people to buy from a store that sells Ds items as well as employs individuals with Ds, I wanted to cry. I was simply embarrassed.

I hear people cry about the lack of community support and services for our children, but I definitely do not see other people jumping up willing to do more. I understand not everyone is in the position to monetarily help out, but there are so many other ways other parents can make a difference. Speak up, spread the word, advocate.

That day, I simply sat at my desk for hours. Not able to comprehend anything after that. At that very moment I was at to the point of just giving up. If other parents don't care, why should I care? But then one look at my amazing son is enough to keep me fighting and pushing. And by fighting for him, I might just win one day... and not only will we be the only ones winning, but the entire Ds community. You might just thank me for my aggressiveness later on.

*(to be continued!)*

You can read the complete blog at [www.twogirlsandethan.blogspot.com](http://www.twogirlsandethan.blogspot.com)

*Nuestra Misión: " la de Crear conciencia y aceptación de niños y adultos con síndrome de Down a través de abogacía, socialización, educación y difusión médica.*

### *Mensaje de Nuestra Presidenta*

Miembros y Familiares,

¡El mes de octubre esta dedicado al síndrome de Down! Tomemos el tiempo para ver hasta donde hemos llegado, donde estamos, y que tan lejos llegaremos.

Nuestro grupo fue establecido en 1974. Hemos trabajado en cambiar palabras como "mongólico" a simplemente "síndrome de Down" y a educar a la gente de lo que es el síndrome de Down. Leyes han cambiado para las escuelas que se enfocan en la educación especial y doctores han sugerido que los bebés se queden en casa bajo la educación de los papas.

En 1991, iniciamos juntas mensuales los Jueves en el Centro de Multi-Servicios ubicado en West Gray. La educación para nuestros hijos, en ese entonces, era un poco de "inclusión" y los avances médicos eran solo para reparar los problemas del corazón. Muchos padres han recibido diagnósis prenatales de síndrome de Down. En enero del 2008, abrimos el Centro de Recursos de síndrome de Down y las juntas mensuales empezaron los sábados en inglés y español. Mas programas y servicios fueron ofrecidos y empleamos a nuestros personales por primera vez. "Inclusión" fue usado en nuestra educación.

En las primeras dos galas en el 2007 y 2008, el dinero recaudado fue usado para abrir una clínica de síndrome de Down en el hospital de Texas Children que sirve a niños desde su nacimiento hasta los 18 años. Nuestro primera directora ejecutiva fue empleada en Julio del 2009. En septiembre del 2009, el programa para la educación de adultos con síndrome de Down (E4L) inicio gracias a una donación de \$35,000 de parte de la fundación de Baxter-Trust. En el 2011, E4L creció hasta los 24 estudiantes inscritos una o dos veces a la semana y nuestro grupo de pantomima dio su primera presentación al publico.

DSAH actualmente sirve a mas de 1,500 familias alrededor de la ciudad de Houston. Colaboramos con otras organizaciones para recaudar fondos junto a otros programas y servicios. Carnastas para los bebés son llevadas a los hospitales para que su educación progrese sobre los años que vienen. Ayuda publica esta disponible localmente, en todo el estado, y nacionalmente.

Hemos logrado semejante progreso para la gente con síndrome de Down y tenemos mucho mas que dar. Invito a cada uno de ustedes que sean parte de nuestros cambios positivos y crecimiento de nuestro grupo. Necesitamos crear un mundo que acepte a nuestros seres queridos con síndrome de Down y un lugar donde puedan lograr su potencia. Cada quien debe poner de nuestra parte. Por favor ofrezca su ayuda voluntaria para poder hacer este progreso posible.

Que tengan un octubre maravilloso. Nos vemos en el torneo de golf y en la reunión de amigos!

**Ann P. Fontenot, S.L.P.**  
Presidente DSAH

### DSAH Octubre Reunión Mensual

**Sábado, 22 de Octubre 2011  
10:00 am y 1:00 pm**

**Presentador: Sr. John Pugh, MA, BCBA**

#### **COMPORTAMIENTO DE TLC**

(ABA) es la ciencia de comportamiento y aprendizaje implementado en los alrededores de un ser individuo. Cambios de comportamiento y aprendizaje ocurren cuando se ajustan ciertas cosas en los alrededores del individuo para promover y mantener el comportamiento deseado. Unas de las fortalezas de ABA viene de la colección de información detallada y análisis. Información del comportamiento demuestra evidencia que el cambio en comportamiento y aprendizaje atribuye con las estrategias usadas y no por otros variables desconocidos.

ABA puede ser semejante efectivo para cualquier individuo siempre y cuando los procedimientos o tratamientos sean consistentemente implementados durante todo el día. El uso mas eficiente de ABA ocurre cuando los principales de ABA se convierten parte de la vida diaria del individuo. Cuando ABA se convierte en una forma de vivir y trata sobre el comportamiento envés de tratarlo como una terapia que ocurre unas cuantas horas a la semana, el comportamiento y aprendizaje se convierten mas eficiente y optimo.

John Pugh es (BCBA). Recibió su especialización de ciencia en psicología de parte de la Universidad sur del estado de Missouri y su maestría de arte en análisis de comportamiento de la Universidad de Houston – Clear Lake. John también recibió entrenamiento específicamente en el tratamiento de el trastorno de comportamiento severo de la institución de Munroe-Meyer en la Universidad de Nebraska – Centro Medico.

Las experiencias de John han incluido programas durante el verano y diarios para niños y adultos con discapacidades que provienen entrenamiento de comportamiento en casa para los niños y familiares, y eso proviene servicios de análisis en clínicas, realizando programas en temas que pertinentes a los análisis del comportamiento, y ofreciendo servicio analítico para varios distritos escolares. La meta de John es que el futuro siga ofreciendo análisis del comportamiento de calidad en casa, escuelas, y en la comunidad.

No se lo pueden perder! Espero verlos en la junta.

**Paula Davis,**

Vice Presidente

## Buddy Walk 2011

Hola Capitanes de Equipos!

Ya casi se acerca el momento de nuestra caminata! Solo nos faltan dos meses para celebrar nuestra **11ava Camina Anual de Amigos** presentada por nuestros amigos de Tricon Energy! Algo sorprendente ha pasado este año! Por primera vez tenemos un **patrocinador presentante!** Tricon Energy se convertido en nuestro **patrocinador a nivel de Platino donando generosamente \$10,000 en honor a Allison Cañas.** A todos los empleados, la gerencia y a **Elva Villafuerte**, la Capitana de este equipo y mama de Allison, les damos nuestras mas sinceros agradecimientos.

Octubre es un mes muy ocupado para el comité de la Caminata. **Tenemos varias fechas limites** que los capitanes deben tener en cuenta para el evento.

**Octubre 28—Cuestionarios de biografías!** Por favor mande su cuestionario para la Carpa de Imagine las Posibilidades a Cindi Condrón al [imagine@dsah.org](mailto:imagine@dsah.org)

**Octubre 28—Ultimo día para que patrocinadores obtengan el logo en la parte de atrás de la camiseta.** Por favor entréguenos todas las formas de patrocinio para que puedan recibir los beneficios. Las formas y logos deben de ser enviadas a [buddywalk@dsah.org](mailto:buddywalk@dsah.org)

Tienen hasta el **5 de noviembre** para asegurar que sus caminantes tengan una camiseta. Así que anótelos en el sistema. Este año las camisetas serán de los siguientes colores: **morado para caminantes**, **amarillo para individuos con SD** y **rojo para voluntarios.**

Solo nos queda la **reunión para capitanes** de Octubre el **10/13**, si usted es nuevo a la caminata, tiene preguntas sobre el sistema o quiere formar su equipo, usted lo puede hacer en esta junta.

Gracias a todos los donantes que nos han ayudado hasta ahora, ustedes son los que nos ayudan a hacer una gran diferencia en nuestra comunidad! Para registrar su equipo, donar, caminar o ser voluntario, visite la pagina

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

**Alejandra Lima**

2011 Buddy Walk Director



Familia Condrón,  
GRACIAS por todo su  
empeño y dedicación a  
la Caminata de Amigos.  
En memoria a  
Gracie a Ally



## Festival Anual de Reunión de Amigos numero 22

*Invite a todos sus familiares y amigos y únase a nosotros para celebrar nuestra 22ava "reunión de amigos". Tendremos premios juegos, concursos, comida y premios por solo asistir! Sin duda será un día especial para hacer nuevas amistades, visitar a las viejas y pasar un buen rato!*

**Domingo, 30 de Octubre 2011**  
**Christa V. Avair Park**  
**15107 Cullen Boulevard, Houston,**  
**Texas, 77047**  
**12:00-5:00 pm**

## Miembros del Club 21



*Por favor, únase a nosotros el  
Sábado, 15 de Octubre  
en el Centro de Recursos  
6:00-9:00 pm  
para nuestro segunda anual*

## Fiesta de Halloween Para Adolescentes / Adultos

**El espacio es limitado y es solo para miembros del Club 21 que reserven su espacio antes del 11 de Octubre al 713.682.7237. No olvide de traer su tarjeta de membresía.**

## Organización busca hermanos de personas con Discapacidades del Desarrollo

¿Está usted o conoce a un hermano de una persona con discapacidades del desarrollo? Una organización ha formado recientemente un programa para mejorar la vida de las personas con discapacidades de desarrollo mediante el apoyo y el empoderamiento de los hermanos y otras a través del apoyo, educación y defensa. Si su respuesta es sí, por favor visite el sitio web SIBscape en [www.sibscape.org](http://www.sibscape.org) o póngase en contacto con Stacey Mather en [stacey@sibscape.org](mailto:stacey@sibscape.org).

## REPORTE DE LA REUNION DE INTERES MEDICO Y APOYO CLINICO DE SINDROME DE DOWN DEL 2011

*Escrito por Sherry Sellers Vinson, MD, MEd de El Centro Meyer en el Hospital de Niños de Texas*

La Dra. Katie Ostermaier, jefe de la Clínica de Síndrome de Down de Houston la cual esta localizada en el Centro Meyer, unidad de Desarrollo Pediátrico en el hospital de Niños de Texas y yo, asistimos a la reunión anual de interés medico sobre el Síndrome de Down y el Simposio Clínico el 5 de Agosto del 2011 en el JW Marriot en San Antonio en conjunción con la convención del Congreso Nacional del Síndrome de Down. Esta reunión incluía a doctores, terapistas, psicólogos, enfermeros y profesores de educación especial los cuales sirven a la comunidad con síndrome de Down. En esta conferencia habían mas de 52 asistentes representando a toda la nación incluyendo a unos de Canadá, Argentina y México. Presente también estaba la Dra. Niru Madduri, la cual era la antigua jefa de la clínica de Síndrome de Down y actualmente la directora de una clínica de síndrome de Down en Nashville, Tennessee.

La reunión empezó a la una de la tarde y termino a las nueve de la noche con solo una hora de descanso para cenar entre 6-7 p.m. El Dr. George Capone, Jefe de la clínica de Síndrome de Down en el Kennedy Krieger Institute/Johns Hopkins School of Medicine en Baltimore, y Dr. Kim McConnell de La Clínica de Síndrome de Down en el Hospital de Niños Gillette en St. Paul, Minnesota, organizaron una junta en la cual proveían créditos de educación continua en el área de medicina por primera vez. El hecho que estos créditos estaban disponibles significaba que la presentaciones eran de muy alta calidad y aprobadas por el consejo medico.

La agenda para las reuniones de DSMIG (por sus siglas en ingles) proveyeron amplio tiempo para discusión y preguntas al igual que la planeación de la reunión del próximo año. Los temas de este ano fueron:

- "Repaso de la Guías de Salud de la Academia Americana de Pediatría para niños con SD" (Las guías mas recientes fueron publicadas 7/29/11) la cual fue presentada por Maria Stanley, MD
- "Condiciones Musculo-esqueletales en Adultos con SD" presentado por Siegfried Pueschel, MD
- "El Adulto con SD: Problemas Médicos, Salud Mental, Cognición, Empleo y Vida" presentada por Nancy Roizen, MD;
- "Investigaciones Clínicas sobre Gráficos de Crecimiento para personas con SD" presentado por Mary Pipan, MD
- "Modelo Computarizado Dinámico de las vías respiratorias en niños con SD" presentado por Sally Shott, MD
- "Archivos de pacientes con síndrome de Down" presentado Brian Skotko, MD
- "Proyector de Investigaciones Clínicas sobre el SD" presentado by George Capone
- "Proyectos Internacionales de SD" presentado por Phil Matteis, MD;
- "Cuidados de Salud de Adultos" presentado por los doctores George Capone, Peter Bulova, y David Smith
- "Panel de Clínicas de SD" constituidos por las clínicas de Maryland, Illinois, Wisconsin, y Pennsylvania.

Aprendí que la mayoría de las clínicas de SD se componen de varias ramas de la medicina y que en todas hay una gran lista de espera para server a sus pacientes como aquí en Houston. Todos estamos buscando una mejor forma de como servir a nuestra comunidad y de como reducir la espera para poder ser visto por estos médicos. Hoy en día la población de adultos con SD esta llegando a edades altas y tenemos que enfocarnos en la calidad de cuidado medico para ellos. Tenemos que asesorarnos en el cuidado de su salud mental al igual que tener investigaciones mas extensas sobre la vida de adultos con SD. Por ejemplo, se cree que los adultos con SD muestran síntomas de degeneración en su espina dorsal C5-6/C6-7 y aunque los doctores de adultos se deben enfocar en tratar estos problemas, debemos también de darnos cuenta que la buena salud esquelética comienza en la niñez. Es recomendado que las personas con síndrome de Down tomen una dosis diaria de Calcio y Vitamina D.

De acuerdo con las nuevas guías de AAP, a los doctores se les esta diciendo que también deben de observar si en los individuos con SD hay problemas alimenticios, apnea de dormir, problemas endocrinos, problemas de visión y audición al igual que la recomendación de la diagnosis de SD a través de un examen de cromosomas de Cariotipo. En adición estas nuevas guías nos dicen que no debemos usar los gráficos de crecimiento actuales para personas con síndrome de Down ya que estos no están marcando la obesidad. Por ahora se deben de usar los gráficos para personas típicas pero se debe de tener en cuenta el Índice de Masa del Cuerpo del paciente hasta que los nuevos gráficos sean disponibles.

## El Teatro Dionysus debuta su show "Bully" en la Convención Nacional de Síndrome de Down

Durante el primer fin de semana de Agosto el teatro de Dionysus viajó a San Antonio para hacer su show "True Confessions of a Bully" la Conferencia Nacional del Síndrome de Down. El Sábado 5 de Agosto, los actores hicieron su presentación ante 80 hermanos de niños y adultos con síndrome de Down. La gran presentación habla sobre el acoso cibernético, el apodarse a la gente y agresión física tuvieron un impacto muy emocional con la audiencia. Después del show los actores tuvieron una sesión con el público en donde una chica estudiante de bachillerato empezó a llorar mientras que recordaba su propia experiencia involucrando a los acosadores de su hermanito.

La presentación del Domingo ante un público de 1,000 personas los dejó llenos de entusiasmo y el teatro Dionysus sintió que habían logrado su meta de promover su misión de inclusión. Esta presentación fue generosamente apoyada económicamente por the Aubrey and Sylvia Farb Community Service Fund.

El elenco de seis personas están emocionados en la participación de otros eventos durante el actual año académico.

El elenco esta compuesto por Cristino Sosa, LaKeicha Thomas, Raymond Deeb, Michael Escamilla, Natalia Borja, Kelly White, Michael Iovine, y Deb Nowinski.

Para más información sobre como tener este show para su escuela u organización, llame a las oficinas del teatro Dionysus al 713.728.0041



### La Asociación Síndrome de Down de Houston

presenta

### HUELLAS EN EL FUTURO

**Sábado, 12 de noviembre 2011 - 9:00 AM - 4:00 PM**

**United Way of Greater Houston**

50 Waugh Drive - Houston, Texas 77007

*¿Qué es la transición? ¿Qué significa? ¿Y qué tiene que hacer para prepararse? Cada paso se explica* - que debemos hacer a partir de la infancia, en la escuela y en la vida adulta de las personas con discapacidad, sus familias y educadores. En esta conferencia, Jo Ann Simons presentará "Huellas del Futuro", que incluye un documento de planificación de la vida diseñado para familias que ofrece un lugar para registrar información específica y personal acerca de sus seres queridos. Vea forma de inscripción en la página 11.

CEU proporcionada por la Universidad de Mujeres de Texas

CPE proporcionado por la Agencia de Educación

## Cuidado de niños los sábados en DSAH está abierto a todas las discapacidades

Nuestro nuevo programa de relevo el sábado en la Asociación Síndrome de Down de Houston ahora aceptan niños con todas las discapacidades de 6 a 14 años. Nuestro nuevo programa se centrará en el trabajo con los participantes en sus habilidades motoras finas y gruesas a través de diversas actividades como la pintura, las artes y la artesanía. Nuestro experimentado personal estará a su disposición para trabajar con los participantes en grupos para ayudar a construir la vida y habilidades sociales.

**Cuándo:** el segundo sábado del mes

08 de octubre, 12 de noviembre, 10 de diciembre

**Hora:** 10:00 am a 4:00 pm

**Dónde:** 7015 W. Tidwell DSRC, Edificio G Suite 108,  
Houston, TX 77092

**Precio:** \$ 30.00 por participante

Para reservar su lugar en nuestro Programa de Respiración sábado, por favor llame al 713.682.7237 o envíenos un correo electrónico a [info@dsah.org](mailto:info@dsah.org) con el nombre del participante, la discapacidad y la información de contacto de los padres.

Debido a las restricciones de instalación, no podemos dar cabida a los participantes en silla de ruedas o médicamente frágiles.

## PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

### Informe clínico sobre la supervisión de la salud para los niños con síndrome de Down

Marilyn J. Bull y el Comité de Genética  
*Pediatría*, originalmente publicado en línea  
25 de julio 2011;

DOI: 10.1542/peds.2011-1605

La versión online de este artículo, junto con información actualizada y servicios, se encuentra en la página: <http://pediatrics.aappublications.org/content/early/2011/07/21/peds.2011-1605>

Las cosas siguen  
mirando hacia arriba

**DSAH TODAY**

# Footprints Into The Future

**Saturday, November 12, 2011**

**9:00 AM – 4:00 PM**

at

**United Way of  
Greater Houston**

**50 Waugh Drive**

**Houston, Texas 77007**



DSAH Members: \$30 each or \$50 for 2 on same registration  
Nonmembers: \$40 each or \$60 for 2 on same registration

CEU's are awarded by Texas Woman's University  
CPE's are awarded by the TEA.

Spanish Translation Provided for Keynote and Selected  
Breakout Sessions.

*Traducción al español para la sesión de  
Jo Ann Simons y otras sesiones estará disponible.*

Keynote by renown author  
Jo Ann Simons

What is transition? What does it mean?  
How do I prepare for it?

Registration: DSAH Members:\$30 each or \$50 for two on  
same registration form  
Nonmembers: \$40 each or \$60 for two on same  
registration form

CPE's are awarded by the TEA for a \$20 fee per person  
CEU's are awarded by Texas Woman's University for a \$25  
fee per person (Social Workers, LPCS, LP, OT, Teachers).



**REGISTRATION**

**Footprints Into The Future**

**Saturday, November 12, 2011  
9:00 AM – 4:00 PM**

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Specialty: \_\_\_\_\_ CEU or CPE Certification: \_\_\_\_\_

Optional Boxed Lunch Session: CHOOSE ONE: \_\_\_ Legal Issues \_\_\_ Baylor Clinic \_\_\_ Evaluations \* \_\_\_ Medicaid Waivers

1:45-2:45 Breakout Sessions: CHOOSE ONE: \_\_\_ IEP \_\_\_ Changing Behaviors \* \_\_\_ Portfolios \_\_\_ When  
Therapy Isn't Enough

Check or Money order made payable to: Down Syndrome Association of Houston

Visa  MasterCard  American Express  Discover

**Total Amount on Card:** \_\_\_\_\_

Card No.: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Name on Card: \_\_\_\_\_

Signature: \_\_\_\_\_

Purchase Order#: \_\_\_\_\_ School District: \_\_\_\_\_

Deadline: November 2, 2011 \* La presentación de Jo Ann Simons y ciertas sesiones serán traducidas al Español\*

With credit card payment,  
you may fax completed  
registration form to:  
713-996-9290  
Return completed form and  
payment to:  
DSAH  
7015 W. Tidwell, Suite  
108  
Houston TX 77092  
Register on line:  
www.DSAH.org

|   |                    |
|---|--------------------|
| 10/1- Gymboree                            | Time: 10am—11am    |
| 10/4 - ECI Staff Meeting                  | Time: 11am-3pm     |
| 10/6 - Education for Life                 | Time: 9am-4pm      |
| 10/6 - Adult Social Club                  | Time: 4pm-6pm      |
| 10/6 - D.A.D.S. Meeting                   | Time: 7pm-9pm      |
| 10/7 - Education for Life                 | Time: 9am-4pm      |
| 10/7 - Adult Social Club                  | Time: 4pm-6pm      |
| 10/7 - Parents Night Out                  | Time: 6:30pm-10pm  |
| 10/8- Saturday Respite                    | Time: 10am-4pm     |
| 10/9 - Diversity Meeting                  | Time: 3pm-5pm      |
| 10/11 - Microboards                       | Time: 10am-2pm     |
| 10/12- Advocacy with The Arc              | Time: 10am-12pm    |
| 10/12 - Katy Com. Group                   | Time: 9am-11am     |
| 10/13-Education for Life                  | Time: 9am-4pm      |
| 10/13-Adult Social Club                   | Time: 4pm-6pm      |
| 10/13- Buddy Walk Team Captain Meeting    | Time: 6pm-8pm      |
| 10/14-Education for Life                  | Time: 9am-4pm      |
| 10/14-Adult Social Club                   | Time: 4pm-6pm      |
| 10/14- Parents Night Out                  | Time: 6:30pm-10pm  |
| 10/15-Gymboree                            | Time: 10am-11am    |
| 10/15-SibClub                             | Time: 11am-2pm     |
| 10/15-Baytown Com Group                   | Time: 10am-12pm    |
| 10/15-Pearland Com. Group                 | Time: 4pm-8pm      |
| 10/12 - Katy Com. Group                   | Time: 9am-11am     |
| 10/15-Club 21 Halloween Party             | Time: 6:pm-9:pm    |
| 10/20-Education for Life                  | Time: 9am-4pm      |
| 10/20-Adult Social Club                   | Time: 4pm-6pm      |
| 10/21-Education for Life                  | Time: 9am-4pm      |
| 10/21-Adult Social Club                   | Time: 4pm-6pm      |
| 10/21- Parents Night Out                  | Time: 6:30pm-10pm  |
| 10/21-Spring Com. Group                   | Time: 7pm-9pm      |
| 10/22-DSAH Monthly Meeting -Behavior TLC  | Time: 10am-3pm     |
| English Meeting / Lunch / Spanish Meeting | 10am / 12pm<br>1pm |
| Alex Angels                               | Time: 11am-12pm    |
| Music Therapy                             | Time: 11am & 1pm   |
| 10/24-Baytown Com. Group                  | Time: 7pm-9pm      |
| 10/25- DSAH Board Meeting                 | Time: 7pm-9pm      |
| 10/27-Education for Life                  | Time: 9am-4pm      |
| 10/27-Adult Social Club                   | Time: 4pm-6pm      |
| 10/28-Education for Life                  | Time: 9am-4pm      |
| 10/28-Adult Social Club                   | Time: 4pm-6pm      |
| 10/28- Parents Night Out                  | Time: 6:30pm-10pm  |
| 10/30- Gathering of Friends Festival      | Time: 12pm-5pm     |

## Community Groups Activity Calendar

### Pearland Community Group

Saturday, October 15 from 4:00pm -8:00pm  
Therapy Spots Annual Fundraiser Dinner - all proceeds benefit DSAH Buddy Walk!  
Epiphany Life Center Church in Pearland  
Spaghetti Dinner, Games, Face Painting, Trick or Treating and More!!  
Pearland@dsah.org for more info

### Spring Community Group

**NEW!!! Child care will be provided/RSVP REQUIRED**  
Friday, October 21 from 7:00pm - 9:00pm  
Buddy Walk 101 Come & Get Inspired!  
Join us at Jumpin' Jak's, 3403 FM 1960 @ T.C. Jester. Pizza, hot wings & drinks will be provided. RSVP REQUIRED by 10.14 to [spring@dsah.org](mailto:spring@dsah.org) for babysitting services!

### Baytown Community Group

Saturday, October 15 from 10am - 12pm  
Baytown Group hits the pumpkin patch!!!  
Baytown First Church of the Nazarene at the corner and Main and 146.  
Baytown@dsah.org for more information

### Katy Community Group

Wednesday October 12 and Saturday October 15 from 9am-11am  
Join the Katy Community Group for coffee and conversation at the Bagel Café on Kingsland and Mason.  
Katy@dsah.org for more info



### Parents Night Out

**FUN** for individuals with disabilities and a **NIGHT OUT** for parents

Parents Night Out is an out-of-home **respite** program for individuals with ALL types of disabilities. Everyone should bring their own snacks and drinks. **Clients Ages 6-14 and Siblings Ages 6-10**  
**For reservations or questions, please contact:**  
**Erin Siao tong** [ESiao tong@eastersealshouston.org](mailto:ESiao tong@eastersealshouston.org) or (713) 838-9050 x 357

Reservations must be made by email or phone by 5:30pm on Wednesday. All families must have a current application completed for each person attending. Times and age groups differ for each location. Check out [www.eastersealshouston.org](http://www.eastersealshouston.org) for more information and applications.

### Reading Clinic with Joanne Mothes

Does your child need help with their reading skills? It is never too early to start. Joanne's clinic provide a one-on-one reading session that will leave you with tips to help your child learn to read or improve their reading.

Class sessions are: October 6, 7, 8, and 10. You must pre-register and request your preferred day and time.

Times available are: AM: 8 9 10 11 and PM: 1 2 3 4 5 6

**Note: Dates & times are given out on a "First Come/First Serve" basis.**

Please complete the information above and mail it together with your payment of \$100, to: Joanne Mothes - 257 Old Spring Lane Dublin, Ohio 43017  
Tel: 614-799-8921 (evenings)

Down Syndrome Resource Center ~ 7015 W. Tidwell, Bldg. G Suite 108 Houston TX 77092.  
713/682-7237 ~ [www.dsah.org](http://www.dsah.org) ~ DSRC is open M-F 9:00a-2:00pm and by appointment only after 2pm

**"DSAH TODAY" is a monthly publication of the Down Syndrome Association of Houston. Please contact the DSAH office at 713-682-7237 if you have any questions about the contents of this newsletter or if you would like to contribute an article.**



Available to all DSAH members from newborns to 6 years old.  
Siblings are welcome!  
"Gymboree Play & Music" is a type of socialization through therapy & music games.

### Sib-Club

This club is exclusively for the siblings of those with Down syndrome ages 6 to 12. In this club the siblings can meet and feel safe expressing their emotions. Food and beverages will be served. FREE to DSAH members but reservations are needed by the day before. Reserve at [sibclub@dsah.org](mailto:sibclub@dsah.org)



### D.A.D.S.

(Dads Appreciating Down Syndrome)

The Houston chapter of DADS is a support system for dads of children with Down syndrome. This group meets the first Thursday of the month at 7pm at the DSRC. For more information or how to get involved, please e-mail us at [dads@dsah.org](mailto:dads@dsah.org)

### Microboards

Interested to know what a Microboard is and how it can help your child with a disability? Join The Arc of Texas and the Texas Microboard Collaboration as they guide families set up their Microboards and schedule PATHS for special needs families.

To reserve your spot please e-mail Cynthia Guiton at [cguiton@thearcoftexas.org](mailto:cguiton@thearcoftexas.org)

### Advocacy with The Arc

Join The Arc of Texas for a summary of The 82nd Legislative Session; How it impacts you; and What you must do now!

Following the wrap-up will be an advocacy planning session, in which participants will identify issues, develop a strategy, and leave with a plan of action for the interim.

RSVP at [www.thearcoftexas.org](http://www.thearcoftexas.org) (under events) or Contact Ginger Mayeaux at 1-800-252-9729 or [gmayeaux@thearcoftexas.org](mailto:gmayeaux@thearcoftexas.org)

Lunch will be provided for those who choose to stay for both sessions.