



DOWN SYNDROME ASSOCIATION
OF ORANGE COUNTY

THE OPTIMIST



WINTER 2010

Investing In A Healthy Future

Just three decades ago, the life expectancy of someone with Down syndrome was just 25 years of age. Since then, advances in medical awareness and technology have more than doubled that lifespan. Yet, there is still much to be done in identifying and treating the medical conditions prevalent in children with Down

syndrome. Early screening and intervention hold the keys to continued progress.

With this in mind, Down Syndrome Association of Orange County has formed an alliance with CHOC Children's to establish a state-of-the-art pediatric clinic focused on children and adolescents with Down syndrome.

Learn more about how you can help provide financial support for the new CHOC Children's Down Syndrome Program. →

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A Message From Our Board President

With the start of a new year, I wish to bring you current on a few changes at the Down Syndrome Association of Orange County.

After serving on the Board for six years, I was recently named President and look forward to serving you and your families for the next two years. Exciting things are happening and we are expanding and improving our offerings.

I succeed Gerard Jensen, whose leadership and passion inspired the Board to dream big and reach new heights. During Gerard's two-year tenure, we initiated many new programs including:

- Collaboration with CHOC Children's, Orange County's pediatric hospital
- Growth of our medical outreach and education program
- The launch of communications campaigns executed in partnership with the National Down Syndrome Congress and National Down Syndrome Society
- Expansion of our educational initiatives across the age and language spectrum
- Partnerships with other disability advocacy and service organizations

I also want to make you aware that Lanny Hardy, who served as our Executive Director for several years, recently stepped down to pursue consulting opportunities. Lanny was instrumental to our organization and he will be greatly missed. We wish him well in his new life adventure. The Board will initiate a search for his successor later this year.

Finally, I wish to thank all of our families for your support this past year. We need your continued help, as we work to grow the organization and serve more families with vital programs and services. Please consider increasing your financial contribution or making a volunteer commitment to DSAOC in 2010. As you know, these are extremely trying times for everyone in California and non-profits like DSAOC have been hit especially hard. Your ongoing personal and financial support is imperative to our mission. Thank you!

Sincerely,

Otis P. Heald III, President
Down Syndrome Association of Orange County

Board of Directors Notes

Volunteer Board members give of their time and talent to provide leadership and direction for the organization. The many people who have served on the Board over the years have grown DSAOC from its grassroots beginnings to a multi-faceted organization. We owe a tremendous amount of gratitude to our past and present Board members.

DSAOC extends its deep appreciation for the dedication and years of service from self-advocate Willie Pestolesi, Brian Sinclair and Ed Underhill, whose terms recently expired. We also welcome new Board members Brenda Deeley, Ira T. Lott, M.D. and Stephanie Ontiveros.

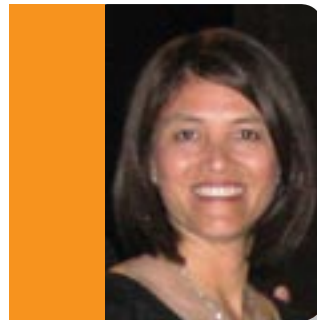
We are currently seeking additional Board members from all walks of life, as well as those who have special skills in legal services, grant writing, human resources and business management. If you are interested in being considered for a Board position, we would love to hear from you. ■



Brenda Deeley



Ira T. Lott, M.D.



Stephanie Ontiveros

*If you're interested...
call the DSAOC Center at
714.540.5794 and leave
a message for Board
President Tres Heald.*

2009 Orange County Buddy Walk

It Was More Than A Walk...



This past November, more than 3,000 people gathered at Angel Stadium of Anaheim for the Buddy Walk to celebrate the lives and accomplishments of people with Down syndrome.

We are pleased to share that despite difficult economic times, individuals and companies gave generously to help DSAOC raise more than \$253,000. This allows DSAOC to continue our core programs including:

- **CHOC Children's Down Syndrome Program** – A new pediatric healthcare clinic for children and adolescents with Down syndrome
- **Partners in Education** – A program that connects educators, therapists, paraprofessionals, and school/district administrators with the training, resources and support needed to help educate students with Down syndrome
- **Mano a Mano** – A program for Spanish speaking families designed to enhance early literacy for children 3-5 years of age, while also helping parents better understand the IEP process and improve their own language skills
- **Teen Club** – Social activities and events for youth ages 12-17 years with Down syndrome

For the first time ever, the Buddy Walk was streamed live on the Internet via DSAOC's Web site. This was due to the courtesy and incredible skills of the people of iBN Sports. You can view the Buddy Walk video at www.dsaoc.org/buddy-walk-2009. ■



It Was A Celebration!



*Save the Date –
Get Involved,
Be Inspired.*
**Orange County
Buddy Walk**
*Sunday,
November 7, 2010*
**Angel Stadium
of Anaheim**

The Orange County Buddy Walk is one of the largest walks in the country and would not be possible without the eager efforts of nearly 150 dedicated volunteers and the support of our sponsors:

- Anaheim Police Department
- Claim Jumper
- Clipped Wings OC Chapter
- The DeSantos Family
- Freeman
- Ed Hackbarth & Family
- iBN Sports
- Jart Direct Mail Services
- KFSH 95.9 the Fish
- Susan A. Katzen Attorney & Counselor at Law
- Krispy Kreme
- Law Offices of Chambers, Noronha & Kubota
- Liberty Capital Management
- Metzger Enterprises
- Orange County Trial Lawyers Association
- Rebel Legion, 501st
- Starbucks
- Sycamore Drum-Line
- Time Warner Cable
- Trinity Episcopal Church
- United Healthcare
- Valero
- Volunteer Clowns of Orange County

Your participation and contributions help DSAOC change perceptions so we can change lives. We are deeply grateful for your generosity. ■

Want to see more photos from the 2009 Buddy Walk? Visit the DSAOC photo gallery at www.dsaoc.org/buddy-walk-photo-gallery

continued from page 1 → The project is directed by Dr. Ira T. Lott, who oversees the CHOC/UCI division of Neurology, while Medical Director of the CHOC Children's Neuroscience Institute. Dr. Anne Tournay, a pediatric neurologist in the CHOC/UCI program is the lead physician in the evaluation of children referred to the clinic. A genetic counselor and research manager of the Down syndrome program, Eric Doran, MS, is the professional coordinator.

We are thrilled to announce that the CHOC Children's Down Syndrome Program opened late last year.

Designed to provide coordinated and comprehensive care, this weekly outpatient clinic provides a turnkey program that offers referrals to a team of pediatric specialists that assists parents with navigating the healthcare system, while educating referring physicians to best practices and the special needs of children with Down syndrome.

"As the neurologist for the Adult Down Syndrome Program at UC Irvine for the past five years, I have been deeply affected by the patients and their families whom I have encountered," said Dr. Anne Tournay. "I look forward to meeting younger patients with Down syndrome and their parents at CHOC Children's."

The physician subspecialty panel includes practitioners from: Cardiology, Endocrinology, Gastroenterology, Genetics, Infectious Disease, Neurology, Neuropsychology, Oncology, Ophthalmology, Orthopedics, Otolaryngology (ear, nose and throat), Rheumatology and Sleep. Experts in developmental and behavioral pediatrics, speech/language pathology, social work, feeding, occupational therapy, physical therapy and psychology provide complete assessments.

DSAOC has committed \$300,000 over four years to help make this unique Down syndrome clinic a reality. Although a large financial commitment, we could not pass on the opportunity to create something of such priceless value. Ideas to expand the effort to adults are already on the offing. Community support is essential to this effort.

We invite you to contribute today to support the largest and most significant project undertaken in DSAOC's history. Let DSAOC know that this initiative is important to you and the children with Down syndrome that it serves by helping us reach our financial goals. ■

CHOC Children's Down Syndrome Program

**Clinic Hours:
Wednesdays 8 a.m. to noon**

**Clinic Location:
CHOC Neurology Center
1120 W. La Veta Avenue,
Suite 125**

Orange, CA 92868

**Appointments:
714-532-7986**



**Ralph Simmons,
Self-Advocate**

***Self-Advocate* Freedom at Last**

Ralph Simmons, a friendly, outgoing, 48 year-old man with Down syndrome presented at the 2009 Education Conference where he spoke to a group of fellow self-advocates about working and living on his own.

Ralph works at Pavilions as a grocery bagger. He says, "The best thing about working at Pavilions is all the new friends I make and just being around people."

Last October, Ralph moved into a one-bedroom apartment after living in a board-and-care group home for 23 years. With help from caregivers, he cooks, cleans, pays bills and takes care of his pet fish, Dr. Pepper. When he puts on his chef's hat, he loves to make soft tacos and chicken quesadillas.

In his free time, Ralph enjoys watching or playing sports, dancing and late night TV. Ralph also bowls every Saturday and enjoys hanging out with his family and friends.

When asked how it feels to be on his own he answered happily, "Freedom at last!" ■

Spotlights

***Volunteer* Support from the Heart**



**Christine Carr,
Volunteer**

For more than two years, Christine Carr has been the volunteer facilitator of the support group for parents of young children ranging from ages 0 to 3.

Christine attended a support group when her daughter LeAnne was about a year old. She realized firsthand the value of a program that brings parents together and found it great for information sharing. Christine also saw that having a confident facilitator who allows everyone to express themselves is what made the support group experience successful. Some of the best information came directly from other parents.

***The 0 to 3 Years
Support Group meets
at the DSAOC Center
the first Thursday
of each month.***

Through DSAOC's 0 to 3 Years Support Group, Christine hopes that parents get a sense of calm, confidence and empowerment that allows them to make a difference and to feel as if they have some control.

Christine brings a heart and passion to the group that is unmatched. "Leading this group is where I'm meant to be," she said. ■

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DOWN SYNDROME ASSOCIATION
OF ORANGE COUNTY

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To be good stewards of the environment and DSAOC's financial resources, we'd like to communicate with you more through e-mail. Please call 714.540.5794 or e-mail kabbas@dsaoc.org today and make sure we have a current e-mail address for you. Thanks!

"What's New at DSAOC?"

Visit the new Web site and Blog at www.dsaoc.org

Communicating valuable, timely information to our families, educators, professionals and others is a top priority. Our new interactive Web site is designed to help keep you informed and up-to-date. You can even RSVP for upcoming events, activities and seminars online. Content is updated frequently – why not make us your home page? Check it out!



Reaching For The Cure Is HOT! HOT! HOT!

The Down Syndrome Association of Orange County is joining the Pediatric Cancer Research Foundation at the Cinco de Mayo Half Marathon on Sunday, May 2. The anticipated event at the Irvine Spectrum Center will raise funds for pediatric cancer research and the new CHOC Children's Down Syndrome Program.

Did you know that, on average, one in every 95 children with Down syndrome will develop leukemia versus a rate of one in every 2,000 children in the general population? While the vast majority of children with Down syndrome will never develop leukemia, the disease remains one of the major health care concerns for our community.

You can sponsor the DSAOC team or register for the half marathon, 10K run, 5K run/walk or 1K kids fun run. The majority of registration fees directly benefits the Pediatric Cancer Research Foundation. However, your sponsorship dollars, plus \$5 from each registration, will benefit the CHOC Children's Down Syndrome Program. ■

REGISTER TODAY!
*Visit <http://www.pcrf-kids.com/reachingforthecure/>
Click "Register Here," and then select
"Join A Team." Our team is listed as
"Down Syndrome Assoc. of OC."
Gracias!*