



SPRING 2014

On Saturday, February 22, more than 250 elegant and fashionable teens and adults with Down syndrome and their guests assembled to enter the Champagne Ballroom of the Doubletree Hotel. The formal red carpet rolled out, and with the use of stanchions, golden balloons, Oscar statues, movie set clapboards and other Hollywood themed decorations, the room was transformed into the DSAOC's version of "A Night at the Oscars."

The evening blended friends, laughter, excitement and delicious food, all wrapped in a comfortable and welcoming ambiance. Our DSAOC Stars posed for formal photos against a Hollywood paparazzi backdrop, and took souvenir photo booth pictures with fun props provided by Shutterbooth. Once the tunes started spinning, the dance floor was full. DJ Willpower "was in the house" getting the party started!

The 2014 Red Carpet Ball Committee, once again, elevated this event to new heights. A big round of applause for Linda and Jillian Leeman, Danielle Borunda, Tatia and Marco Huipe, Kristin Abbas, Pat Wiggins and Cindy Lysek for their time, energy and creative talents.

The Red Carpet Ball is an annual dinner and dance for individuals with Down syndrome, age 15 and older, and their guests. A significant portion of the Red Carpet Ball is funded by generous donors. We sincerely thank: Wayne Richards, Thomas McDaniel, the Rossman family, JB Interiors Drywall, Heather Moeck, The King's Inn, Sean Rosenthal from Within A Dream Photography, the Leeman family, AVMS Lighting, and Mater Dei's Chuckles for Charity group for their generosity in providing donations to support this year's event. It certainly wouldn't be a party without our Stars, so thank YOU for making it another great event!









continued on page 4



Message from the President

Dear DSAOC Families,

My name is Janette Mattson, and I am proudly serving my sixth year on the Board and second term as president. DSAOC is a wonderful organization of families, caregivers and community supporters, and I'm

thrilled to be part of such a dedicated team that is working hard to achieve our goals and mission.

My loving husband, Tim, and I have been married for 24 years, and have three amazing children. Spencer is in his first year at UC Irvine, and Luke is a sophomore at Orange Lutheran High School. Our third child, Becca, has Down syndrome. She is 11-years-old and attends Villa Park Elementary as a 5th grader. Our entire family has been involved with DSAOC for more than 10 years, and have enjoyed attending and volunteering at many activities and events.

I am pleased to welcome back the DSAOC Optimist Newsletter! We recognize that the resources and stories that it has brought to you in prior years are irreplaceable, and we are thrilled to offer this newsletter semi-annually as another means to communicate the extraordinary things that DSAOC is doing. We welcome your ideas on articles or information to share in future newsletters, so please contact the DSAOC Center.

Some of you may already know that DSAOC recently celebrated 35 years of service. Over the years, the DSAOC Board of Directors has accomplished some amazing things. We've grown from serving a handful of families to the Organization that you see today, which serves more than 1,500 individuals with Down syndrome and their families throughout greater Orange County.

The DSAOC Board of Directors continues to evaluate the greatest needs within our community, and has adopted several goals for its 2014-15 term year. Certain goals are related to adding resources for teen/adult services, expanding our hospital and healthcare provider outreach program, and increasing our programs for elementary age children. We are currently seeking committee members in several areas to help DSAOC achieve its goals.

Contact the DSAOC Center, if you wish to become more involved, including volunteering, becoming a member of a Committee or Board, or simply offering feedback or ideas.

Thank you for your support of DSAOC! We look forward to hearing from you, and hopefully seeing you and your family at one of our upcoming programs, activities or events. You can view more information, including our monthly Fridge Post and calendar of events, by visiting our website at www.dsaoc.org.

Sincerely,

Janette Mattson President - Board of Directors, DSAOC



Karen Azling



Kristin Griffin



Sara Hamilton



Gerard Jensen, Ph.D.



Mike G. King, Esq.



Ira T. Lott, M.D.



Stephanie Ontiveros



Richard Peterson, M.D.R.



Ruben Rivas



Kelly Sackett



David Unter

What's the Buzz...

The statewide housing crisis facing adults with developmental disabilities is starkly evident in Orange County, which is home to 17,000 individuals with such disabilities as Down syndrome, autism spectrum disorder, intellectual, epilepsy and cerebral palsy.

Finding affordable housing in Orange County is a challenge even for those without developmental disabilities that are on a very limited income. According to the Social Security Administration (as of January 2014), the SSI independent living rate is \$877.40 per month for an adult living on his/her own. Some individuals may receive less, depending on their work status. The 2013 average fair market rent is \$1,440 countywide for a one-bedroom apartment. Without a subsidized housing option, this would require 164% of an individual's income to fund just his/her housing cost.

Most of these adults are struggling unsuccessfully to reach their modest goal of securing safe, decent and affordable housing in the communities in which they were born, raised, educated and now working. They are priced out of the most basic one-bedroom rental apartments in Orange County. In addition, most are forced to continue living with their aging parents, who are often ill equipped to care for themselves, much less adult children with special needs.

People with developmental disabilities are the sons and daughters, grandsons and granddaughters of families and neighbors in Orange County. They should be part of a lasting and mutually beneficial relationship that involves the community as a whole. At Regional Center of Orange County (RCOC), we believe in having as many choices as possible, and have included some different living options on our website at www.rcocdd.com. Education on housing options is vital.

The Family Autism Network is sponsoring a presentation by Legacy Homes and Golden State Pooled Trust on **Tuesday, May 20, from 5 to 7 p.m.** at Pretend City in Irvine. This option is for families that want to provide for anyone who is unable to live independently, whether or not they are identified as "disabled." There will be a discussion on the issues families should consider and new ways to plan for lifetime care. To view the flyer and RSVP information, please visit **www.faninfo.org** and search Legacy Homes.

You may contact your RCOC Service Coordinator at any time to discuss other living options for your son or daughter. To learn more about the housing advocacy efforts of RCOC, countywide and in your city, please e-mail **DDhousing@rcocdd.com**.

Did You Know...



Orange County is currently experiencing an increase in measles cases, and more cases are expected to arise over the next several months. Measles are highly contagious and can spread rapidly through the air. Orange County has the highest number of measles cases in California for 2014, and has been featured on national newscasts, because of the recent outbreak.

For information about the MMR vaccine for infants and young children, please visit: www.ochealthinfo.com/phs/about/dcepi/epi/disease/measles and www.ochealthinfo.com/phs/about/family/iz/children. You can also call the Orange County Health Care Agency Health Referral Line at (800) 564-8448.

If your child has not received his/her immunizations, we urge you to discuss this issue with your child's healthcare provider.

2014 Orange County Buddy Walk

It's Always More Than A Walk...It's A Celebration!

Grab your calendars, and make note that you and your family will spend **Sunday**, **November 2**, at the Angel Stadium of Anaheim for the best celebration of the year – the Orange County Buddy Walk!

This is an event for the entire family, and your participation and fundraising efforts aid DSAOC's local programs, services and support groups, as well as the National Down Syndrome Society's (NDSS) national advocacy programs.

We are excited to announce that this year will include a **NEW** registration system and fundraising software! This is thrilling news for most of us who had to endure issues with the old system. NDSS is still disseminating information and training details, but we plan to hold a special Team Captain event this summer, so STAY TUNED.

Get Involved, Be Inspired.

Orange County Buddy Walk

Sunday, November 2, 2014 9 a.m. to 2 p.m.

Angel Stadium of Anaheim

Save the Date

Never been to the Orange County Buddy Walk? Take a look at all the fun exhibitors, exciting attractions, awesome live bands and family connections that take place during this event. View our photo galleries on our website at: www.dsaoc.org/buddy-walk-photo-gallery.html

You can also view last year's Orange County Buddy Walk video by visiting: www.vimeo.com/78948973

Watch your e-mail in-box in July for Orange County Buddy Walk news. If you aren't currently receiving e-mails from DSAOC, please call the DSAOC Center at (714) 540-5794, and provide your preferred e-mail, or contact us at **admin@dsaoc.org** and ask to be added to the e-mail list.

The Orange County Buddy Walk is one of DSAOC's largest and vital fundraisers. Your registration dollars and additional fundraising efforts are very much appreciated and greatly needed. Your support allows DSAOC to provide a place for advocacy, connection, and hope for families and their loved ones with Down syndrome. Thank you in advance for your generosity!



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For more information about the Red Carpet Ball, please visit: www.dsaoc.org/red-carpet-ball.html

Interested in becoming involved with this event? If you would like information about becoming an RCB Committee Member, or if you'd like to make a monetary contribution toward this event, please contact Kellie Perez at kperez@dsaoc.org or call the DSAOC Center. RCB Committee Meetings are held monthly to plan themes, funding, decorations, and other ideas to make the RCB exciting and successful. We look forward to your support!



View photos from the 2014 Red Carpet Ball: Sean Rosenthal: Within a Dream Photography

flickr.com/#/photos/withinadream/sets/72157642223164605/



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www.shutteryou.com/photobooth/13371084/doubletree-hilton-hotel-santa-ana-orange-county-airport-santa-ana/ca/celebration/shutterbooth



CHOC 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, the Down Syndrome Association of Orange County formed an alliance with CHOC Children's in 2009 to establish a state-of-the-art pediatric clinic focused on children and adolescents with Down syndrome.

The **CHOC Children's Down Syndrome Program** is an outpatient clinic designed to provide coordinated and comprehensive care. The Program 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.

Why would you bring your child with Down syndrome to this clinic?

- For diagnosis and treatment of neurological conditions, such as behavioral problems, autistic symptoms or seizures
- To assess the need for a specialty referral
- To be assured that your child is up-to-date with the current healthcare quidelines

What are the top health concerns drawing families to this clinic?

- To obtain a wellness opinion based on the current healthcare guidelines
- To identify problems in development and behavior
- To receive second opinion consultation

The Clinic Director is Ira T. Lott, MD, and the Clinic Physician is Anne Tournay, MD. The clinic's Professional Coordinator is Eric Doran, MS, and the Administrative Coordinator is Alicia Hernandez.

CHOC Children's Down Syndrome Program

Clinic Hours:

Wednesdays 1 to 5 p.m.

Clinic Location:

CHOC Neurology Center 1120 West La Veta Avenue Suite 125 Orange, CA 92868

Appointments:

Phone (888) 770-2462 Fax (855) 246-2329

The clinic is assisted by nurses, social workers and other staff from CHOC Children's. Together, the clinical team has over 50 years of experience in providing care for individuals with Down syndrome.

For more information on the CHOC Children's Down Syndrome Program, please visit **www.dsaoc.org/chocs-children-down-syndrome-program.html** or call the DSAOC Center at (714) 540-5794.



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ORGANIZATION
PAID
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DOWN SYNDROME ASSOCIATION

OF ORANGE COUNTY

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Community Corner

Creating Awareness in Our Community and Beyond...

Sharing the stories of individuals with Down syndrome and the people and organizations making a difference in their lives.

Launched in October of 2012, during Down Syndrome Awareness Month, **Community Corner** debuted with "Rachel's Story" that quickly generated more than 100 views and many positive comments of hope and inspiration.

DSAOC is investing time and money into this exciting awareness project, because we believe these stories must be told. They are on our website, and can easily be shared and accessed from almost anywhere.

There are currently six episodes in our awareness video series with the seventh soon on its way. You can help spread awareness by sharing these video links with your friends and family and posting them on your social media sites. Ask your friends and family to post them on their sites, too.

With a couple clicks of your mouse, you can create awareness that can Change Perceptions and Change Lives.

View DSAOC's "Community Corner" Down syndrome awareness series: www.dsaoc.org/community-corner.html

Interested in supporting DSAOC's Community Corner Awareness Project? The Humphrey's family recently made a contribution towards the Community Corner awareness project, and you can, too! Make a contribution to DSAOC, note that it is for Community Corner, and your name/family's name will be recognized in the credits of the episode you help fund. For more information on supporting this project, please contact Kellie Perez at kperez@dsaoc.org. Thank you!

Design Courtesy of:

