



DOWN SYNDROME ASSOCIATION
OF ORANGE COUNTY

THE OPTIMIST



FALL 2011

It's More Than A Walk...

It's a Celebration!

Join more than 2,500 supporters, as we unite to celebrate the lives of our loved ones with Down syndrome.

Orange County Buddy Walk

Sunday, November 6th
Angel Stadium of Anaheim
9 a.m. to 2 p.m.

Get involved, be inspired. Be a part of one of the largest Buddy Walks in the nation, and show your support for the Down Syndrome Association of Orange County, the National Down Syndrome Society and all individuals with Down syndrome.

Visit our website at www.dsaoc.org for registration and event details.

We look forward to seeing you there! →



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Message from Board President Tres Heald

As we move into the final quarter of 2011, DSAOC remains very busy, preparing for our annual Orange County Buddy Walk at Angel Stadium of Anaheim. This event is an inspiring celebration for people with Down syndrome, their families and friends. It is also the largest annual fundraiser for DSAOC; funding many of the annual programs, services and activities we all need and love. If you haven't already registered or made a donation, please consider doing so today. You can visit our website at www.dsaoc.org for more information.

Besides being a fun-filled day, it's a great networking opportunity for parents and caregivers. I have heard people say, "I had no idea there were so many families in greater Orange County touched by Down syndrome. When we got to the Buddy Walk, we realized we were part of a huge family!"

In addition to the Buddy Walk, the DSAOC Center continues to host many weekly activities and seminars to inform parents/caregivers, and offer social and networking opportunities for individuals with Down syndrome and their families. In addition, we continue to develop new ideas and welcome you, our constituents, to provide feedback. Please do not hesitate to give us a call at

(714) 540-5794 or send us an e-mail at info@dsaoc.org to provide input on what we are doing well, and to let us know how we can better serve you and our community. There is so much that we want to do, and your ideas will help us focus on what is most important to you.

Since our summer newsletter, I am happy to report that we have added three new board members to the DSAOC team: Ruben Rivas, Lisa Lilienthal and Dana Miranda. Ruben, Lisa and Dana are all parents of children with Down syndrome. They also bring valuable professional expertise in the fields of management, public relations and public policy to our Board. DSAOC would like to publicly thank them for their service to our organization and the families we serve. As I have written in past newsletters, I encourage you to donate your time and expertise to our cause, as well. Our greatest asset is represented by you, our families and friends.

Finally, this will be my last post to the newsletter as president of the DSAOC Board of Directors. After serving for two years, I will be turning over this important role to our next president. While I will remain on the Board, we will be installing new officers for the New Year, and they will begin their terms January 1, 2012. I am very grateful to have been trusted with this responsibility, and wish to →

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Board of Directors Notes

Welcome new Board members Ruben Rivas, Lisa Lilienthal and Dana Miranda. We are currently seeking additional Board members from all walks of life, as well as those who have special skills in legal services, human resources and business management. If you are interested in being considered for a Board position, we would love to hear from you.

Are you interested in learning more about the role of a Board member and the time commitment required?

Don't let questions like this keep you from inquiring about this opportunity. If you're interested or have questions, call the DSAOC Center at (714) 540-5794 and your call will be directed accordingly. ■



Ruben Rivas



Lisa Lilienthal



Dana Miranda

*If you're interested...
call the DSAOC Center at
(714) 540-5794
for information.*

“I Don’t Know”

by Kathie Snow

Three little words—“I love you”—are considered the most important words we can say. But three other little words—“I don’t know”—could also have a profoundly important effect on the lives of children and adults with disabilities and their families. They could prevent the death of dreams, equalize relationships, open up worlds of possibilities, and much more. The use of these words by parents, physicians, educators, service providers, and anyone else who touches the life of a person with a disability could radically change that person’s life!

Let’s start at the beginning—D-Day—the day of diagnosis. Many, if not most, physicians who diagnose developmental disabilities in children are usually pretty certain in their prognoses: they tell parents what their child will never do. The physician’s words have the power to turn the dreams of the parents into a nightmare of hopelessness and fear.

Some parents never recover, and their children, sadly, suffer the consequences of their parents’ emotions and the physician’s prescription: a lifetime of treatments, interventions, and services to “cure” the child or minimize the effects of the condition; limited opportunities to experience a full life as a child or adult; segregation in special programs; low expectations; and more. Other parents, however, discover the doctor was wrong the first time their child exceeds the predicted low expectations. But this discovery might take years—years in which hopelessness, fear, and the never-ending merry-go-round of services and treatments have taken over the family’s life. These parents may be able to chart a new and better future for their children, but they may never recover their original hopes and dreams. The physician’s predictions created a wound of despair that’s too deep.

The erroneous prognosis may lead to another negative outcome: mistrust. Many parents may sarcastically laugh about the ignorance of the “dumb doctor who didn’t know what he was talking about,” and they also learn not to trust any “experts.” Their operating principle—with just cause—becomes, “Fool me once, shame on you; fool me twice, shame on me.” Parents may be reluctant to enter into positive, trusting, equal partnerships with any professionals.

A physician’s dire predictions about a child may be the result of the doctor’s ignorance. After all, diagnosing physicians are usually pediatric specialists who have little or no real-life experience with, or knowledge about, adults with developmental disabilities. Thus, they don’t know what’s really possible! In addition, physicians may spew the “worst-case” scenario to protect themselves from future lawsuits: they fear being sued by parents if they predict a “rosy” future for a child and it doesn’t come to pass.

How could all this change if diagnosing physicians realized they don’t have all the answers and said, I DON’T KNOW more often? Instead of prophecies of doom and gloom, what if the doctor said something like, “I don’t know if your child will [do this-or-that]...” which could be followed by:

- “Anything’s possible...” or
- “If your daughter is not able to [walk or talk or whatever], we can look at some great assistive technology devices that could help...” or
- “Let’s focus on what’s really important for your child: that she feels good about herself, that you believe in her, and that you have dreams for her...”

And how the physician delivers this message would be critically important. Saying, “I don’t know...” tinged with a look of pity or sympathy would negate the spoken words.

While this type of message might not cause the parents to jump for joy (they still might feel concern for their child’s future), it wouldn’t strip parents of the hopes and dreams all parents need to successfully raise their children. The doctor who diagnosed my then four-month-old son with cerebral palsy was certain in his doom-and-gloom prognosis. But the second doctor we saw routinely said, “I don’t know...” or “I’m not sure...” and his words helped restore some of the hope the first doctor had stolen. Like most parents, I wasn’t looking for guarantees or promises, only a more realistic and truthful appraisal. And when it comes to forecasting the future of a child or adult with a disability, I DON’T KNOW is the most honest statement that can be made!

What about others adopting the I DON’T KNOW response? Parents of very young children don’t yet have →

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“I Don’t Know”

by Kathie Snow

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the wisdom borne from experience, so the words of therapists, service providers, and other early childhood staffers can have great influence on how mothers and fathers think about their child and her future. During these early years, parents are looking to the experts for reassurance and hope. Instead, many professionals seem to routinely dole out fear-generating warnings, such as, “If your child doesn’t do [such-and-such] by [certain age], then [this awful situation will result]...” These are someone’s opinions—not facts! So those who work with young children and their families can omit harmful opinions, and use responses similar to those recommended for physicians.

Moving on to school-aged children, teachers, administrators, and others in the school system can also learn to say I DON’T KNOW more often. Special ed teachers, principals, and others in the educational arena also have the power to crush the dreams of parents and their children. Consider parents who are hoping their young child with a disability will enter a general ed classroom in kindergarten or first grade, instead of an ungraded, segregated special ed classroom. What if, instead of automatically saying, “No,” to this request, a principal responded with, “We might not know exactly how to do this, but we’ll work together and figure it out...”

We could apply the same scenario to adults with disabilities, regarding where and how they live and work. Instead of assuming a person couldn’t be successful in a real job or living on his own, what if service providers said, “We don’t know for sure that this will work, but we’re sure gonna’ give it a try...”

Finally, what about parents? While others may routinely dash our hopes and dreams for our children, do we, in turn, do the same to our precious sons and daughters? If a child with a physical disability wants to play on the park and rec softball team, do his parents tell him, “No! You use a

wheelchair—you can’t do that!” What about a teenager with a cognitive disability who says he wants to go to college or a young adult who wants to marry his true love? What happens when parents say, “No” to these ordinary—but very, very precious—hopes of their children? Instead of trying to “protect” their children (and crushing their dreams at the same time), what if parents let go of their fears, and wondered to themselves, “I don’t know if this is possible, but it might be...” In turn, they could say to their child, “We’re not sure how this would work out, but we’d like to hear your ideas about it...”

I DON’T KNOW—said out loud or silently in our heads—can open our minds to solutions and possibilities! We really don’t know what’s possible, what’s do-able, what will work or won’t, until we try! Here are some phrases that can exercise our mouths and our brains:

- I don’t know...let’s talk about it.
- I don’t know, but anything’s possible...
- I don’t know...what do you think?
- I don’t know, so let’s figure this out together.
- I don’t know—we’ve never done this before, but we can give it a try!
- I don’t know, so let’s get some others involved to see what we can come up with...

If you think it might be difficult to say these words, practice in your head or in front of the mirror when no one else is around—practice makes perfect, right? Then when the time is right, you will be able to say the words and mean them, and a world of possibilities will be opened! ■

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DSAOC's Resource Library

CHECK IT OUT!

As a reminder, the DSAOC Center has a multi-media resource library available to our families and the community. This resource library contains books, DVDs, tapes, educational games and other material that you can check-out free of charge for up to one month at a time.

We are very excited to let you know that we have purchased two new books for our resource library!

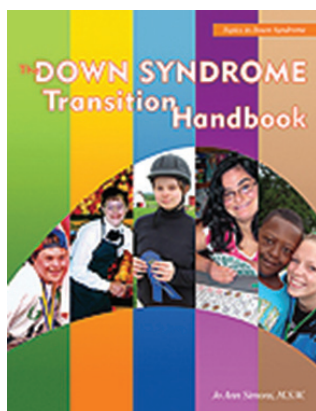
Additionally, we've received a generous donation of DVDs on health and nutrition from Dr. William Sears.

The Down Syndrome Transition Handbook

Charting Your Child's Course to Adulthood

Jo Ann Simmons, M.S.W.

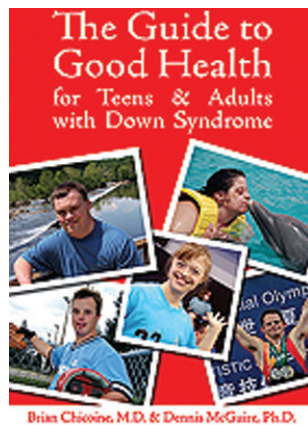
Full of practical tips and step-by-step instructions, this invaluable guide helps families with the enormous task of planning for their child's future. Topics include: how to apply for benefits, find housing, seek employment, set-up a financial plan, and address legal and guardianship issues. All children deserve a well-planned, secure and independent future; this book is the first step toward making that happen for people with special needs.



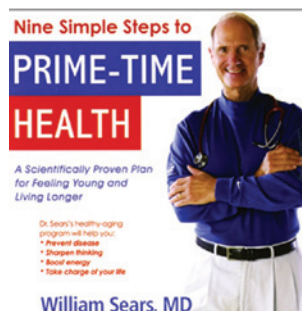
The Guide to Good Health for Teens & Adults with Down Syndrome

Brian Chicoine, M.D. & Dennis McGuire, Ph.D.

Drs. Chicoine & McGuire, specialists in the care of adults with Down syndrome, offer their



expertise in this essential guide for parents and families. Covering every issue and condition, it offers the best information on promoting a healthy lifestyle and recognizing potential medical problems to ensure appropriate care and the best outcome. With the current generation of people with Down syndrome living longer than ever before, parents and caregivers can reference this book to learn what to expect and how to provide excellent care for their children, as they grow older.



Nine Simple Steps to Prime-Time Health DVD

A Scientifically Proven Plan for Feeling Young and Living Longer
William Sears, M.D.

On this DVD, Dr. William Sears shares Nine Simple Steps to Prime-Time Health from his new

book, and an "up close and personal" interview with his wife, Martha, along with a number of other health related tips.

Dr. William Sears' healthy-aging program will help you:

- Prevent disease
- Sharpen thinking
- Boost energy
- Take charge of your life

Dr. Sears has been advising busy parents on how to raise healthier families for almost 40 years. He continues to do so today, along with his two oldest sons, at the Sears Family Medical Practice in San Clemente, CA. ■

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thank everyone with whom I have worked. Your staff at the DSAOC works extremely hard and has done an excellent job over the past two years. Kellie Perez, Kristin Abbas and Alicia Sanchez welcome your e-mails, calls and feedback. DSAOC has a dynamic Board of Directors filled with dedicated, hard-working people, and I am confident they will serve you well in the next term. So, while I am stepping down from my role as president, I have no doubt that the

DSAOC will be in very good hands, as we take on the years ahead with great vision, leadership and hope. ■

Regards,

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

Partners in Education

Presentation and NEW Website Launch...

On October 13th, DSAOC held the first **Partners In Education** (PIE) presentation for the 2011-12 school year. We were thrilled to have educational teams, early intervention specialists, preschool teachers, transition program staff and parents/caregivers in attendance, representing several districts.

Our featured speaker, Dr. Richard Peterson, shared his insight, as well as great tips on how to work within the educational system and collaborate effectively with all members of a student's IEP team. The many stories and examples Dr. Peterson shared really highlighted the importance of clear communication and complete IEP documentation.

The PIE program is designed to build partnerships, in order to help shape meaningful education for students with Down syndrome. We share research-based techniques, approaches and materials that have been successfully implemented in educational programs for students with Down syndrome of all ages and grade levels. It is our goal to

support educators by providing training and other tools that teachers and therapists can use in their efforts to ensure that all students with Down syndrome reach their maximum potential.

DSAOC also announced the launch of our new online resources for the **Partners in Education** program. This new section of our website can be found by visiting our homepage at www.dsaoc.org and clicking on the 'Educators' image.

We are eager for you to help us continue to build this site by sharing resources and tools that can assist educators, therapists and others, who serve children with Down syndrome. Please forward your thoughts to Sandi Ames, DSAOC's Education Consultant, at sames@dsaoc.org or by mailing information and resources to the DSAOC Center, 151 Kalmus Drive, Suite M-5, Costa Mesa, CA 92626. You are always welcome to call DSAOC at (714) 540-5794. ■



CHOC Children's Down Syndrome Program

An alliance between the Down Syndrome Association of Orange County and CHOC Children's

The CHOC Children's Down Syndrome Program is nearing its two-year anniversary of serving our families. This program has fulfilled important needs for our community by offering parents and caregivers sound medical advice and referrals to specialists who understand the health care needs of children with Down syndrome.

Community support continues to be essential to this effort. Expansion will be necessary to meet the growing list of children waiting to be assessed or needing second opinions regarding their medical issues. You can show your support today by making a contribution to DSAOC dedicated to this alliance.

DSAOC would like to recognize the following foundations and corporations for their contributions that have supported the CHOC Children's Down Syndrome Program and our other health education programs:

- Pacific Life Foundation
- The Allergan Foundation
- Valero Energy
- Clipped Wings, Orange County Chapter

Clinic hours are:
Wednesdays from
8 a.m. to 12 p.m.

Clinic location:
CHOC Neurology Center
1120 West La Veta Avenue
Orange, CA 92868

To schedule an appointment,
call (714) 532-7986.

For more information on the CHOC Children's Down Syndrome Program and this alliance, please contact the DSAOC Center at (714) 540-5794. ■

DSAOC wants to hear from you! Contact us today at (714) 540-5794 or kperez@dsaoc.org to share your CHOC Children's Down Syndrome Program experience. Help us let other families know the benefits this program is providing to our Down syndrome community.





**Parth Bhatt,
Self-Advocate**

Self-Advocate "Never say never!"

From day one of Parth's life, his family made a commitment to involve him in as many opportunities as possible. This commitment has continued for 22 years, with many more exciting adventures to come.

Parth's family feels they have been very lucky to have such wonderful teachers that have touched his life and given him confidence to believe he can achieve anything he puts his mind to. This is also the way his family has raised him. Parth never says never! He is willing to try almost anything, at least once.

Following the lead of his brother, Shyam, and his cousins, Saunil and Ruchi, Parth wanted to do all the things they were doing. This included activities in school and in the community.

Parth enjoys sports and is an experienced skier and swimmer. He is the first individual with Down syndrome to participate with the TVI Actors Studio, where he is currently taking acting classes. He shows-off his acting talents every Tuesday evening at DSAOC's Theradrama program. Parth has also been in Tae Kwon Do for three years, where he has learned to focus more and gain overall confidence. And, you better watch out for him on the dance floor... he has taken several dance classes and especially likes hip-hop and salsa!

"It takes effort and commitment to get Parth everywhere he needs to go, but it's worth it," say his parents. "The entire family will pull together to get him to all of his classes and activities, but Parth has such a great personality, he is wonderful to be around and our family members flock to him."

Parth's parents also enjoy the networking and overall social opportunities they receive through everything he is involved with. "We meet other parents who have children with Down syndrome, and it's great to see Parth making new friends, too. He is amazing!" ■

Spotlights

Volunteers "We are a team!"

With such a small staff, DSAOC relies heavily upon the support of our strong volunteer connections, particularly with our annual fundraisers.

Each June, DSAOC holds its annual Golf Tournament, Banquet & Auction. This fundraiser keeps staff very busy in the months leading up to this event, not to mention how much work it is the day of the tournament.

New and returning volunteers give their valuable time each year to help us on the green, in the auction and banquet area, and at the registration booth. We couldn't operate such a great tournament without their help!

There is a special volunteer team that takes on the 'Lead Course Volunteer' role, which is an extremely important task. This task needs to be coordinated by volunteers who are organized, dedicated and have great hospitality skills. They also need to understand the game of golf and know their way around the course.

DSAOC has been very lucky to have two wonderful volunteers who join us each year, and have done so since 2007. Buc Duke and Jack Naylor are responsible for transporting all sponsors and volunteers to their designated holes on the course and for ensuring they all receive lunch and beverages. At the conclusion of the tournament, they pick everyone up and transport them back to the registration area. If you are one of those volunteers or sponsors on the course all day, you especially appreciate Buc and Jack's role during this event.

With all of the other aspects involved in coordinating a golf tournament, it's a great feeling to know that you are turning over a very important task to people who can manage it without fail. Buc and Jack are 'take charge' guys, who know what needs to be done, and they do it with a smile, which makes our event even more memorable for those who come in contact with this volunteer team.

Besides being involved with our annual golf tournament, both Buc and Jack have been long-time supporters of DSAOC through their connection with the Underhill family, which has a young son with Down syndrome.

Thank you, Buc and Jack, for all you continue to do for DSAOC and our families. We appreciate you, and are honored to recognize your volunteer service! ■



**Jack Naylor and Buc Duke,
Volunteers**

**Orange County
Buddy Walk
Sunday,
November 6th
Angel Stadium
of Anaheim**

Stay Connected to DSAOC

Visit www.dsaoc.org today to access these convenient ways to stay connected to DSAOC and the latest Orange County news related to Down syndrome.



It's More Than A Walk...

It's a Celebration!

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The Buddy Walk is DSAOC's largest annual fundraiser and awareness building event. Money raised supports a number of programs and services provided by DSAOC that educate parents and caregivers, while enriching the lives of people with Down syndrome and their families. With your generous participation and contributions, the Buddy Walk makes the following programs possible:

→ **Parent Education Program** – Helps parents of children with Down syndrome navigate the first five years of their child's life. This includes hospital/home visits by staff and trained Parent Mentors, annual educa-



tional seminars, new parent orientation guides and a 'Welcome Baby Basket,' as well as access to DSAOC's multi-media resource library.

→ **Hospital Outreach** – DSAOC trained volunteers visit local labor & delivery hospitals and clinics providing up-to-date information on Down syndrome and important resources for new parents, as well as hospital staff.

→ **Special Presentations and Support Groups** – Presentations cover topics relating to all age groups, including health care issues, alternative therapies, safety, education advocacy and more. Support groups are currently offered for expectant parents and families who have children ages 0 to 11 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 four to six years-of-age, while helping parents understand how to work at home with their child. As a result, parents better understand the IEP process and improve their own English language skills.

→ **CHOC Children's Down Syndrome Program** – A pediatric health care clinic for children and adolescents with Down syndrome.

→ **Teen Club & Friends Up 4 Fun** – Social activities and events for teens and adults with Down syndrome.

To date, we have 107 teams this year, and anticipate a few more joining before the October 30th deadline. If you haven't yet formed your team, please do so soon. You can still register as an individual leading up to the day of the event.

You don't want to miss out! Register today. ■



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What have some Team Captains done this year to raise money and awareness?

Ana Gonzalez, team DHR Love Syndrome

Ana's company holds monthly awareness activities for employees. In August, they focused on Down syndrome, in honor of Ana's niece, Olivia. Employees were asked to wear yellow and/or yellow ribbons in honor of Down syndrome awareness and, if all 55 employees responded, the company would donate to a Down syndrome organization.

Ana was thrilled that all employees embraced this awareness event. As a result, her company donated \$500 to her Buddy Walk team.

A big THANK YOU to Ana, DHR and her employees!



Jackie Hunter, team Jayda's Jammin' Crew

Jackie initiated the task of creating her own fundraiser, complete with wine tasting, a drawing and a fun environment for all attendees. Since she lives in Temecula, she had access to several wonderful wineries. On August 28th, Jackie held her first annual Wine Tasting Fundraiser at Falkner Winery! All proceeds benefited her daughter's Buddy Walk team. Jackie's event was even featured in one of the local newspapers. How exciting!

At DSAOC, we recognize the time and effort needed to host fundraisers. We appreciate all that Jackie did to help raise awareness of Down syndrome and raise funds for DSAOC and NDSS. Thank you!



Patricia Park, team Pepperdine Special Education Advocacy Clinic

Patricia gathered Pepperdine students and organized a Bake Sale! This was done to rally fellow students to join the team and create awareness of Down syndrome, while raising money for DSAOC's programs and services.

The first Bake Sale was held in early October, during which they raised more than \$245, primarily from students. They have a second Bake Sale scheduled soon at which Patricia hopes to involve more of the Pepperdine faculty. Way to go Patricia, and to all of the students supporting this initiative at Pepperdine! ■



Upcoming DSAOC Seminars and Workshops

Look for these exciting topics coming to your Fridge Post and e-mail soon...

We are excited to give you a sneak peek at select seminar and workshop topics that are on the schedule for 2012. Besides education and health care, you will notice an extensive series of topics addressing teen and adult issues, as well as some that deal directly with specific concerns about a child's development, such as social skills and student readiness.

Be sure to take advantage of these informative seminars and workshops by making time to join us and the expert presenters we have scheduled.

Partners in Education (PIE) Workshops

Education is one of the most important steps towards empowerment. Whether a parent, educator or individual with Down syndrome, having the knowledge of what options are available opens doors to opportunity.

Helping Students Be Successful in The Learning Process, presented by Dr. Jan Weiner – Professor of Special Education at California State University, Fullerton

History Perspective and Evidence-based Best Practice Determining Best Outcomes, presented by Dr. Jan Weiner – Professor of Special Education at California State University, Fullerton

Parent Education Workshops

These workshops are designed to provide parents with an overview of the service delivery system for students with Down syndrome, with a focus on the IEP process. Sandi Ames, DSAOC's Education Consultant, shares her knowledge and expertise, while also bringing in guest speakers. These workshops are available in English and Spanish throughout the year.

IEP Workshops

Saturday IEP Clinics

Goals and Objectives

Determining a Student's Least Restrictive Environment

Transition to Public School: IEP for the Young Child

Assessments

Assistive Technology Options

Teen and Adult Series - Seminars & Workshops

These workshops are developed to support teens and adults with Down syndrome, along with their families. We will also be offering Saturday mini-conferences, utilizing several resources for teens and adults with Down syndrome and their parents/caregivers.

Internet Safety

Transportation & Safety

Conservatorship and Power of Attorney

SSI Benefits

Living Options

Lanternman and Other Community Support Options

Self Advocacy Education for Life and Future

Stories from Successful Peers in the Community

Self Esteem, Opportunity, Responsibility

Transition Program Options

Post Education Options - Colleges

Employment Options

Connecting to the Right Employment Program

Supports Necessary for Independence

Healthcare Series Seminars

These seminars are offered as part of DSAOC's Health-care Education & Outreach program. We wish to educate parents on the health care issues prevalent in children with Down syndrome, so they are stronger advocates for their child, as well as assist with early detection of possible health issues. DSAOC engages medical professionals from CHOC and UCI to present on a variety of topics.

Dual Diagnosis – Down Syndrome & Autism

Genetics and Down Syndrome

New Healthcare Guidelines for Early Childhood

Ear, Nose and Throat Issues in Individuals with Down Syndrome

Behavior Issues and Modifications ■



DOWN SYNDROME ASSOCIATION
OF ORANGE COUNTY

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