



# MAKING THE Connection

AUGUST 2014 • DOWN SYNDROME CONNECTION OF THE BAY AREA

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## Gala for Giving

Nancy LaBelle

The Gala for Giving was a magical and successful evening, held May 3 at the beautiful Diablo Country Club. Thanks to a generous outpouring of auction item donations (including silent, live, and dessert) and ticket purchases, we raised \$109,000 gross from the festivities. This is our fourth year hosting a spring gala, and this year I'm happy to say we had wonderful community support with 300 guests, a 33% increase in attendance.

Thank you to our event sponsors: Chevron, Nordstrom, Diablo Country Club, and Fremont Bank. Thank you also to our business VIP table sponsors: Wells Fargo, Farmers/Herzog Insurance and Bakers Hughes. We are grateful to our families and friends who purchased VIP tables this year: Garcia, VandenBerghe, Zolnier, Dereschuk, Guerrero, and the Brabant and Tuma families. Thank you to Bob and Jean Ryan for pouring tastings of Occasio wines and to John Kinney of Occasio Winery and Landmark Vineyards for providing wine with dinner for everyone.

We were grateful to have Jennifer and Chris Dodge, our member speakers for the evening, who eloquently shared their very personal story about bringing their beautiful daughter Ainsley into the world. We listened as they talked honestly about their journey to understanding and acceptance and their deep love for family. Also, we were so very fortunate to have Mark Ibanez from KTVU Channel 2 whose personality, sense of humor, and compassion made him a phenomenal addition as Master of Ceremonies for the night. Mark kept everyone informed about the Warriors and even rescued a cake the Dereschuk family purchased for \$1,100. You had to be there! Mark was moved by our organization. If schedules work out, he says he will be with us again next year—and we would be happy to have him. We were honored to have Concord Mayor Grayson and his wife, Danville Mayor Storer and his wife, and Contra Costa County District Attorney Dominique Yancy in attendance this year. Concord Mayor, Tim Grayson, spoke proudly about his sister who has Down syndrome.



Mark Ibanez

Thank you to our Auctioneer, Dennis McCormac, a true professional who has been with us for five years. Dennis always does an amazing job, with conviction in his voice, bringing in the money for our programs. A big thanks goes to Nicole Gee of Nicole Gee Photography; she captured the evening with her talent, as you see in the beautiful photos. We were also fortunate to have Lindsay Noonan of Lindsay Lauren Events volunteer

GALA, continued on page 4



Above: guest member speakers Jennifer and Chris Dodge



GALA FOR GIVING PHOTOGRAPHY: NICOLE GEE PHOTOGRAPHY

Thank you to our 2014 Gala Sponsors

### NORDSTROM



OCCASIO WINERY



FREMONT BANK



# Down Syndrome Connection OF THE BAY AREA

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### 2014 Board Meetings

The Board meets monthly on the 3rd Tuesday from 6–8 p.m: Aug. 19, Sep. 16, Oct. 21, Nov. 18. To attend or bring a guest, please call the Board President, Mike Zolnier, at 925-819-1009.

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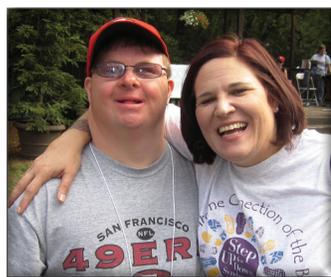
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## Welcome Keri and Joseph

*Marianne Iversen*

We are so pleased to announce the addition of Keri Klass and Joseph Vaughn to our staff. Both are Administrative Assistants and help in numerous ways around the office assisting with a wide variety of tasks. We are grateful to have dedicated and hardworking employees like Keri and Joseph on the DSCBA team!



## Grateful to Terese

*Nancy LaBelle*

The DSCBA has been blessed, and I personally was honored, to have a wonderful

president, Terese Ghilarducci, leading our Board of Directors for the past three years.

Terese insists that Martha Hogan secretly groomed her for the position since she was eight years old. This is when she became part of the Hogan's extended family and, as Terese would tell you, was joined at the hip with Blair.

During her term as president, Terese led our board with passion and dedication. She was a true leader through a challenging time of change and growth. Among many contributions, with the DSCBA team, she updated the board member Application, as well as bylaws for member and officer terms. She created and implemented the Whistleblower and Conflict of Interest policies, in addition to attending and volunteering at many fundraising events.

From 1998 to 2006 Terese also served as board secretary of the DSCBA. As a licensed Marriage and Family Therapist, Terese has worked with siblings of DSCBA families for years. Sibling Support with Terese remains available via group or individual sessions at the DSCBA. Needless to say, Terese has given and continues to give much to this place she loves.

We will miss her but know she will continue to be part of all of our lives here at the Connection, as she is a wonderful friend.

## Board President's Message

*Mike Zolnier*

Hello DSCBA members and friends,

On May 1, 2014, I proudly started my three-year term as president of the DSCBA Board of Directors, after serving as board member alongside my wife, Karen, for two years. I am thrilled to take on a leadership role at this amazing organization, which dedicates its time and effort to ensuring that people of all ages born with Down syndrome and their families are fully supported throughout their life journey. I look forward to working with DSCBA Executive Director Nancy LaBelle and the entire staff. It is an honor to serve and to be in a position to make a difference for families who have someone they love with Down syndrome. I want to take this opportunity to thank Terese Ghilarducci, former board president, for her three years of dedicated service and steadfast commitment to the mission of the DSCBA.

A bit about me. For my wife and me, the best day of our lives was October 1, 2008, when our first child, Mason Ansley Zolnier, was born. As amazing as this day was, it rocked our world when we heard the words, "We believe your son was born with Down syndrome"! Fast forward five and a half years, and I can truly say the impact of having beautiful Mason in our lives has been profound. Where we once felt torn down to the core, our foundation is very strong now. We have grown into better, more patient people because of the experience. Honestly, it has been a long, tough journey and one that we know will have many speed bumps ahead; however, we would not change a thing!

The DSCBA has been the most important resource in my core and extended family's lives since Mason was born. In the past three years, our family has raised more than \$50,000 just by sending out a webpage for the Step Up for Down Syndrome Walk. I am asking that you all think about what the DSCBA means to you now and what it has meant to you in the past—and to get involved in the Step Up walk this year. Our goal is to raise \$150,000, and we cannot be successful without everyone's commitment.

We are always looking for energetic people to join our board. Board meetings are held every third Tuesday of the month at the Danville DSCBA. If you would like to visit our meetings, please email me at [mike@vdbprop.com](mailto:mike@vdbprop.com).

I am delighted to be in a position to give something back to an organization that for more than 16 years has been a critical lifeline for Bay Area families. As board president, I look forward to meeting many DSCBA members and families in the coming years.

Have a great summer!



## STAY SOCIALLY CONNECTED



*Check us out on Facebook at  
[www.facebook.com/dscba](http://www.facebook.com/dscba)*

*Get updates from the Connection and learn about events  
Fans can post text, photos, and video to this page*

*Over 1,800 followers now...*

*Why don't you become one too?*



*GALA, continued from page 1*

to create a beautiful candy buffet and Dina Madanat from Floravida Events, who generously designed beautiful VIP table flower arrangements that we all enjoyed.

For those of you who have never organized and hosted a party for 300, I tell everyone, "It's a piece of cake—like throwing a wedding on steroids." It's got all the fancy, crazy details of a wedding, then you throw in all the fundraising aspects, and you're there. This evening would not happen without an amazing staff at the DSCBA working on all the details: Kathy Harkins, Marianne Iversen, Peggy Alreck-Anthony, and Nancy Ferguson. The event would not run like a machine and exude the elegance it does without our event planner Kshama Perera with eWeddings and Events; she is like family to us. The evening would be a total flop without our volunteers, almost 40 of them. They work hard behind the scenes and literally run on the night of the Gala to keep the processes seamless.

We raised over \$21,000 on the Fund-a-Need portion of our live auction. This part of the auction asks everyone to give whatever they can to our DS Educational Alliance and the programs and services we provide through that partnership. This outpouring of generosity tells me that our members and the community understand how critical it is for us to continue our quest to educate educators in Bay Area school districts, provide a voice to children of all ages, advocate for inclusion, prepare children for success in school, and to offer ability awareness services to foster acceptance and friendship. We do all this in the hopes that everyone, as they work hard toward independence at any age, will be welcome, accepted, and never underestimated in what they can achieve.

Thank you for your support and for your attendance on this beautiful evening. I hope you will join us again next year on May 5, 2015.

*Gala photos continued through page 6*







## Aktion Club and Fourth of July

Marianne Iversen

The Aktion Club held a fundraiser at the Kiwanis Danville July 4th Parade. The members came up with the idea to sell lemonade, and it was a great success. The proceeds from the event will be used to give back to the community, either by donating to a local non-profit group or by buying supplies for a charity organization in need. The Aktion Club is a service organization that is open to all adults living with disabilities who want to become community leaders and provide service to others. Amazing things happen when the members discover their talents and put them to use. The Aktion Club is co-sponsored by the San Ramon Valley Kiwanis and the Down Syndrome Connection of the Bay Area. If you know of anyone who might be interested in joining this group, please contact Marianne@dsconnection.org. This is a wonderful opportunity to give back to the community.



Above left: the stand where refreshing lemonade was found

Directly above: Blair Hogan and Paul Byer of SRV Kiwanis

Left: walking and selling lemonade

Gala photos continued from page 5



2014 FALL–WINTER

Schedule of DSCBA Classes and Parent to Parent Groups

DANVILLE LOCATION CLASSES

**MUSIC THERAPY**

Saturday: 10:00–11:30 a.m.  
Aug. 9, Sep. 6, Oct. 11, Nov. 1, Dec. 13,

**BABY & ME** (formerly Baby Steps)

Wednesday: 10:30 a.m. –12:00 p.m.  
Aug. 20, Sep. 17, Oct. 15, Nov. 19, no Dec. meeting

**SMALL STEPS**

Monday: 3:30–5:00 p.m.  
Session 1: Sep. 15, 22, 29, Oct. 6, 13, 20,  
Session 2: Nov. 3, 17, Dec. 1, 8, 15

**STEPPIN’ UP**

Wednesday: 4:00–5:30 p.m.  
Session 1: Sep. 17, 24, Oct. 1, 8, 15, 22  
Session 2: Nov. 5, 12, 19, Dec. 3, 10, 17

**NEXT STEP**

Tuesday: 4:00–5:30 p.m.  
Session 1: Sep. 16, 23, 30, Oct. 7, 14, 21  
Session 2: Nov. 4, 18, Dec. 2, 9, 16

**STEP IN**

Thursday: 4:00–5:30 p.m.  
Session 1: Sept. 18, 25, Oct. 2, 9, 16, 23  
Session 2: Nov. 6, 13, 20, Dec. 4, 11, 18

ADULT CLASSES THROUGHOUT THE BAY AREA

**SF STEP (SAN FRANCISCO)**

Tuesday: 4:00–5:30 p.m.  
Session 1: Sep. 16, 23, 30, Oct. 7, 14, 21  
Session 2: Nov. 4, 18, Dec. 2, 9, 16

**STEP OUT (OAKLAND)**

Wednesday: 4:00–5:30 p.m.  
Session 1: Sep. 17, 24, Oct. 1, 8, 15, 22  
Session 2: Nov. 5, 12, 19, Dec. 3, 10, 17

**BENICIA STEP**

Wednesday: 4:00–5:30 p.m.  
Session 1– Sept. 17, 24, Oct. 1, 8, 15, 22  
Session 2– Nov. 5, 12, 19, Dec. 3, 10, 17

For questions or to RSVP before meetings

Contact Marianne at 925-362-8660, or check the website:

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

PARENT TO PARENT GROUPS

**PARENTS WITH CHILDREN AGES 0–3**

Facilitator: Martha Hogan  
Location: DSCBA, Danville  
Tuesday: 7:00–9:00 p.m.  
Oct. 28

**PARENTS WITH SCHOOL-AGED CHILDREN**

Facilitator: Martha Hogan  
Location: DSCBA, Danville  
Wednesday: 7:00–9:00 p.m.  
Sept. 17, Nov. 19

**PARENTS WITH TEEN AND ADULT CHILDREN**

Facilitators: Marianne Iversen and Tamara Reed  
Location: DSCBA, Danville  
Thursday: 7:00–9:00 p.m.  
Aug. 21, Oct. 16

**GRANDPARENT TO GRANDPARENT**

Facilitator: Martha Hogan  
Location: DSCBA, Danville  
Wednesday: 10:00 a.m.–11:30 a.m.  
Aug. 27, Sept. 24, Oct. 22, no Nov. meeting,  
Dec. 3

**PARENT MENTOR**

The Parent Mentor program consists of parents who have been trained to mentor a new family or a family that has moved into the Greater Bay Area. Mentors will be matched with a family according to location, needs, and common interest. For more information, please contact Martha Hogan at [Martha@dsconnection.org](mailto:Martha@dsconnection.org), 925-362-8660.

**SIBLING TO SIBLING**

Facilitator: Terese Ghilarducci  
If you are interested in learning about the possibility of a sibling group, please call the Connection at 925-362-8660.

Step In Works on Health and Wellness

Tamara Reed

During the last few months, the Step In themes were about healthy lifestyle, nutrition, and healthy relationships. Angela Stanford from Vital



Nutrition & Wellness started us off with everyday tips for mindful eating. Angela taught us how to make healthy choices when planning meals or eating out. She shared her knowledge of nutritious foods, gardening, and even healthy recipes for sweet treats. Thank you, Angela! Step In had a great time getting to know you.

As a complement to our healthy lifestyle theme, Step In welcomed Stephanie Ross and Lennie Olbrycht from Two Left Feet Dance Center in Danville. Stephanie and Lennie taught us Nia, a sensory-based movement practice. These classes were fun and really got us moving. Stephanie had us up and swaying with the music, using our voices and bodies, and having a great dance party! Lennie taught a form of movement called Ageless Grace, which consists of 21 simple exercise tools designed for all ages and abilities. We enjoyed music and dance activities while seated in a chair. What fun that was! Who knew you could work so hard and have so much fun while sitting down? Thank you so much to Stephanie and Lennie for sharing their time and talent. Step In had a wonderful time!

At top: Angela Stanford

Below: The Step In gang with Lennie (second from left)



Upcoming Schedule of Events

OCTOBER 5

Step Up for Down Syndrome Walk & Family Picnic (see page 10-11 for details)

DECEMBER 7

DSCBA Holiday Party

JANUARY 24, 2015

DSCBA Inclusion Summit for Parents

## Cooking Up Some Healthy Fun

*Tamara Reed*



The Benicia Step Group loves to cook together. In keeping with the theme of better health and wellness, we decided this year to change some favorite menu items into healthier alternatives, and a healthier dinner party was planned. In January we remade a favorite meatball and pasta dinner with turkey and quinoa meatballs, brown rice and quinoa pasta, sugar-free homemade sauce, homemade whole grain garlic bread sticks, and a big salad. For dessert we tried a healthier version of peanut butter chocolate kiss cookies. A week later, after all menu items were prepped and sampled, we sat down to a terrific dinner with friends. There were thumbs up all around the table for this well planned and tasty meal!



Top left: Martin Gonsalves, Andrew Vasquez, and Rachel Warren making cookies  
At left: Damien Carlon

## Improvising Sticky Situations

**SF Step**

*Harold Burns*

This semester the SF Step crew continued to explore relationship dynamics through improvisational theater. Topics included break ups, holding boundaries with friends, saying "No, thank you," asking someone on a romantic or friend date, and navigating inclusiveness among a group of friends. We also acknowledged and supported Emma Darby during her mother's time in hospice and subsequent death. We would like to send a special shout out to Nina, Emma Yungert, and Shanna as they prepare for their upcoming dance performances and to Robert as he prepares for his clown performance! Finally, we send a big thank you to our fun and faithful volunteer Wendy Earl!



Emma Darby



At right: from left: Robert Humphreys, Emma Yungert, Nina Krietzman, Shana Jimenez, Christina Lewis, and Chris Vidales

## Together, We Do Step Out

*Harold Burns*



A true circle of friends at Step Out

The Step Out team did some deep soul-searching this semester as we explored anger and frustration. We found deep commonalities in our struggles. Everyone shared the pain and frustration of feeling inadequate, especially around learning. We also shared the powerful ways we confront those feelings and relieve both acute and chronic stress. Strategies included deep breaths, reading a favorite book, going to a safe quiet space to be alone, positive self-affirmations, sharing our feelings with supportive friends, and dancing. We also dove into the importance of perseverance in the face of challenges that persist. We enjoyed having Virginia Bonham return as a volunteer to help facilitate some of these self-awareness exercises.

We send special congratulations to Annika Miller, who got a job through Project Search and is now placed at UCSF!

Step Out was happy to welcome Chris Corr-Barberis, a great new addition to our circle of friends!

## What Is Smooth, Silky, and Cool?

### Small Steps Class

Laura Briggs

One of the most fun, and oftentimes most difficult, medium to play with is shaving cream. Smooth, silky, and cool—you would think that everyone would like it, but not so. For some who are tactilely defensive, it can be very difficult. So we add spoons, sticks, and even gloves for those who really want to touch it but just can't make themselves. Then we all have a great time.



Hannah Fletcher, Logan Silliman, and Ainsley Dodge



Above: Lulu Jensen



Above: Leah Quintella, Adam Villaflor, Lucas Paterno

## Thank you to Ashley Stringfellow with Flaunt Boutique of Danville

The boutique generously opened its doors in February for a full day of shopping for the DSCBA. We were so grateful to receive a generous check for the proceeds, and we thank everyone who came out to shop. The fundraiser was in honor of Mason Zolnier and the Zolnier family.



Mason Zolnier



Karen Zolnier and Ashley Stringfellow

Consider shopping at Flaunt  
145 E Prospect Avenue  
for beautiful designer clothing



## Next Step—Full of Heart and Talent

Marianne Iversen



Above: the Next Step group on Valentine's Day

The Next Step class worked on several different heart-themed projects over the course of the last several months. In February they created heart wreaths made from tissue paper, which they proudly hung in the office. In subsequent classes, they worked on creating a unique piece of artwork that was sold at the Gala. They textured a canvas with glue and then painted it. After painting, they added a decoupage heart, words, and string hearts they had made in a previous class.

Below: Nicky Lowe, Christian James, and Patrick Harkins



For Mother's Day, each student wrote a love message to their Mom, held them up for a photo, and then gave the photo as a gift. Together, the pictures made a wonderful collage that is hanging in the office.



Above: finished artwork for the Gala

Below: Our Mother's Day collage





# It's time to **Step Up** for



Down Syndrome Connection  
OF THE BAY AREA

## Top 10 reasons to 'Step-Up' for Down syndrome and the DSCBA

- 1 The DSCBA is the **ONLY** Bay Area organization that serves the specific needs of people of all ages born with Down syndrome and their families.
- 2 We ask our members, friends, and family to fundraise **ONCE A YEAR**.
- 3 If your family has benefitted from the DSCBA, this is a great way to **GIVE BACK**, and also honor your loved one.
- 4 It will make you **FEEL GOOD**, and it also gives the people you ask an opportunity to give to an organization that has impacted your lives, which feels good.
- 5 Step Up donations are equal to 25% of our annual budget. Your efforts literally keep our **DOORS OPEN!** Many of our services are free to hundreds of families a year: new parent counseling and education, partnership with Bay Area schools/IEP support, support groups for all family members, AAC consultation, books and communication device lending libraries, Baby & Me class, and so much more. We are not government funded!
- 6 It takes 15 **MINUTES** to make a fundraising page and email it out to everyone you know. No calling, door knocking or face-to-face requests. People can choose to give if they are able.
- 7 90 families raised \$130,000 online last year. Just think if **EVERYONE** sent out a page.
- 8 **CAN'T ATTEND** or live out of the area? Register as a Virtual Walker from around the globe for free. Tell grandparents, aunts, uncles, siblings, and friends to register as a Virtual Walker and create their own page too!
- 9 Your outreach for donations about our organization **PROMOTES AWARENESS**. Social media outlets allow you to advocate quickly and with big results.
- 10 **NOT TECH SAVVY?** – NO problem! Call the DSCBA, and we will create your page for you. All you have to do is email it out to everyone you know.

**2014 Goal: \$150,000**

**BE PART OF OUR SUCCESS AND GET STARTED TODAY**

**<http://www.firstgiving.com/stepup2014>**

**The number one reason people say they don't give is because they aren't asked.**



Sponsored by 

# Down Syndrome

**Win**

**Great prizes will be awarded to...**

- Walk teams that raise the most money – 1st, 2nd & 3rd place
- Walk team with largest team in attendance
- Walk teams with the most creative T-shirt design – 1st, 2nd & 3rd place

**ENTERTAINMENT**  
 for all ages including:  
 Bouncy House, Rock wall,  
 Tattoo Artist, Music,  
 Dancing, Fishing  
 (trout pond), Carnival  
 Games and MORE

**Sunday October 5**  
 Little Hills Ranch  
 18013 Bollinger Canyon Road  
 San Ramon, CA

## Schedule

- Registration 10:30 – 11:30 a.m.
- Festivities Begin 10:30 a.m.
- Walk Begins Noon
- Lunch 1:00 – 2:30 p.m.
- Festivities end 3:30 p.m.

Costs: \$30 per person (Children under 6 and those with Down syndrome are always free)

## What should we bring with us to the walk?

Bring offline donations you have yet to turn in, a cooler of goodies if you would like anything other than lunch provided, your walk T-shirt(s), sunscreen, comfortable walking shoes, good quality stroller, money for raffle tickets, and a great attitude!

NOTE: Cell phones do NOT work in the park and the immediate surrounding area.



## Jennifer's Education Corner

### IEP Success Stories from the DSCBA

#### Preparation - Education - Advocacy - Communication

Jennifer Cooper, DSCBA Director of Parent Support & Education



As in most years, this past spring I spent a lot of time with families concerning IEPs (Individual Education Plans). Hours were spent prepping for IEPs, strategizing, reviewing and attending IEPs, and reviewing goals. The IEP process is one that can be stressful, draining, confusing, and consuming for families. I brace myself for the onslaught of long meetings, IEPs with 60 or more pages, and often contentious dealings with districts. This spring welcomed a series of unexpected success stories from which I've tried to learn from and want to share.

Some of the issues that families were dealing with included wanting a specific service (e.g., music therapy) that the district had previously fought and denied, wanting their children to remain in a general education setting, wanting more academic goals or behavior supports added to the IEP, and wanting a child to be retained in a grade. Here are the common threads that I've tried to pull from these scenarios:

*"This past spring welcomed a series of unexpected success stories from which I've tried to learn from and want to share."*

**Prepare in advance.** These families listened and noted the cues and signs that the district was presenting and tried to organize their response and strategy.

**Identify and unify your team.** The families lined up their support and showed those cards to the district. Some had legal or DSC representation—or both; several had outside specialists (i.e., an outside SLP, doctor, or educator) who supported their viewpoints. Districts often listen more effectively when there is a unified opinion and/or diversif-

fied support for a specific service or placement issue. Unfortunately, parent opinion alone often isn't strong enough to convince districts of something contrary to their opinion.

**Don't be afraid to squeak.** In all cases, these are families who made it clear to the district that they will go the extra mile to fight for their child's rights and best chance at educational success. Several of the families had legal representation in previous years. It's somewhat of an unfortunate reality that the squeaky wheel gets the grease.

**Keep relationships as positive and trusting as possible.** Even when these parents disagreed (or were poised to disagree) with the district proposals, they showed a willingness to be civil, to listen to the district's perspectives, to explore and visit proposed changes to placement, and to communicate as openly as possible. In all the cases, the final IEP felt unified and positive. More progress can be made when you foster positive and trusting relationships.

I'm optimistic that this season was the beginning of a new trend: more productive and positive IEPs with districts. Families are becoming increasingly empowered on their own and through our offered education and IEP trainings and groups. We are able and ready to provide families with supports, consultation, research-based information, and articles related to the educational needs of children with Down syndrome. Please let us know how we can support you and your child in their next IEP.

**Note:** To see additional and generalized tips on having successful IEPs, search for the Wrightslaw article "8 Steps to Better IEP Meetings: Play Hearts, not Poker." See another helpful article from the Kids Together, Inc. website at: [www.kidstogether.org/IEP.htm](http://www.kidstogether.org/IEP.htm).

## DSEA Update: Collaborative Efforts

Jennifer Cooper

The Down Syndrome Educational Alliance made a strong presence and impact in the 2013-2014 school year. We held 30 trainings where we managed to educate 560 educators and 437 students in 15 different Bay Area districts. We shared information about Down syndrome, curriculum adaptations, literacy and AAC, and inclusion and ability awareness. Trainings were well attended and received positive feedback; most importantly, we received several reports of improved classroom situations that sprung out of our supports.

Through the process of witnessing and participating in those improved classroom scenarios, a couple things were again confirmed. One, there is no *one-size-fits-all* model for educating students with Down syndrome. We continue to learn, adapt, and collaborate with educators and families to try to develop the most successful scenario and supports for each student. Two, this collaborative process is at the heart of these improved relations and is the heart of the Alliance.

*Collaborative Efforts, see page 13*

### 2014 Fall Classes for Educators

#### Thanks to the DS Educational Alliance Program

- Speech Intelligibility in the Down Syndrome Population
- DS 101
- Visual Supports for Communication and Literacy
- Visionary Training
- Ability Awareness

For questions regarding upcoming trainings, or to schedule a training in your district, please contact Nancy Ferguson, DSEA Program Manager, at [Nferguson@dsconnection.org](mailto:Nferguson@dsconnection.org) or 925-362-8660

## Feeding Development in the Down Syndrome Population

Heather Peterson, MS, SLP-CCC

### Collaborative Efforts, from page 12

When all parties at the table can respectfully and openly come together to share ideas, questions, resources, and strategies, it's a win-win for students, educators, and families.

The collaborative process must have a foundation of mutual goals, shared responsibility, accountability and resources. Also needed is the development of trust, respect, and a sense of community (Cook, L. and Friend, M. 2010). A strong IEP is the first step to ensuring that this process can take place. Students need meaningful goals that can be met and woven into their environment. For example, if they are in a general education setting, the goals should be able to be looped into the grade Core Curriculum standards. Times for team meetings and home/school communication methods can be noted in the IEP. The designation of roles and responsibilities needs to be clarified. Most importantly, it is hoped that there is general agreement and consensus with the goals and general content and services of the IEP. When the whole team works toward the same goals, efficacy and successes increase.

We hope that you work together with your child's team to develop a strong IEP. Keep in mind, we are always happy to consult with you prior to and after IEP meetings. We can't attend every IEP meeting, but if you know it's going to be a challenging or pivotal meeting, please inquire as to our availability. Also, in the fall, we will have back-to-school parent folders with tips and information about working successfully with your child's team. Please come by the DSCBA to pick one up or to talk with one of us about additional DSEA resources that might benefit your child and his/her education team.

It wasn't until recently that I realized that I hadn't written any articles on feeding development, feeding difficulties, or the relationship of feeding and speech development. Perhaps because I have recently been treating a lot more children with severe feeding difficulties, this has come to my attention. No matter what degree of feeding difficulties your child has, there is a dramatic relationship between feeding development in the way it relates to your child's oral motor function and speech clarity. Here is a description of the types of feeding difficulties that walk through my door daily, and why they occur.



**Child A** eats everything that the family eats, stuffs his mouth, and is quite messy during meal-time. The child drinks from a straw but the tongue wraps under the straw and can often be seen protruding from his lips. The parents often don't think there is a feeding difficulty. **WHY:** This is a child that either has some chewing ability or none. He often chews three times then swallows the food whole because his tongue and jaw are not working properly to hold food on his molars while chewing. He often cannot feel what's going on in his mouth. He has unresolved tongue protrusion and a low open jaw position that affects his speech development. This child has dysarthria of speech.

**Child B** eats crunchy, dissolvable things like crackers and chips and prefers purees and softer foods like bananas, cheese, ground meats (chicken nuggets), etc. This child lacks fresh fruits, vegetables, and, often, meats. **WHY:** She eats crunchy, dissolvable foods because these foods provide her with sensory awareness when they crunch. She can feel these specific foods but has such reduced sensation and overall oral skills that dissolvable foods are safest. Soft solids are also safe because the child can mash them with her tongue on the roof of her mouth and suckle or swallow them without chewing. You may think she chews because her mouth looks like it's going up and down, but it's really tongue movement, not the jaw. This child has tongue protrusion, open mouth posture, and decreased speech clarity. This child also has dysarthria of speech.

**Child C** drinks only one type of juice and eats the same limited brand-specific foods each day. You have to pack food for this child every time you eat out at a restaurant. His diet is often nutrient depleted. **WHY:** His food choices are controlled by subconscious or very obvious fear. He has extremely limited skill in his jaw, tongue, and lips. He watches you make, place, and feed him his food. This child's oral sensory profile may be characterized as tactile defensiveness or mixed sensation. Tactile defensiveness is a learned tendency to respond negatively or emotionally to tactile input. Mixed sensation means that within their oral cavity, a child can have a combination of hypersensitivity (over-reaction to stimulus), hyposensitivity (underreaction to stimulus), or normalized sensitivity. This can be very confusing for a child to process and to manage food. This child often has Apraxia of Speech coupled with dysarthria.

**Child D** is over the age of three, only drinks milk or PediaSure from a baby bottle, and perhaps eats purees or baby food—but maybe not. This child is nutrient depleted. **WHY:** This child lacks the ability to move her jaw up and down in a chewing manner because she has never done it. She may swing her jaw side to side regularly. She has very low muscle tone and strength in her entire body and has practiced an infantile suckling pattern for years on her baby bottle. Her tongue thrust is large, and she would not know how to manage food if she tried, which she never would. She is hyposensitive in her mouth. This child is void of a variety of nutrients that children need to grow and interact. This child can be mistakenly diagnosed with Apraxia but needs intensive oral motor work to strengthen and create motor patterns for speech development.

All of these feeding difficulties are caused by low oral tone, low muscle strength, and differences in sensitivity. They can all be improved and better normalized with therapy targeting the above areas. These children have speech clarity difficulties because all of the above mentioned oral skills need to be present while learning to speak and producing speech. I'm happy to talk to you more about your child. Please contact me if you think your child needs an Oral Placement and Feeding Evaluation: [heather@happykidstherapy.com](mailto:heather@happykidstherapy.com).



### Olivia's Jamming at UCLA

*Lili Byers*

Hola, I'm Olivia Byers-Straus. I'm just finishing my first year in the UCLA Pathway program, and here I am at my first UCLA



Dance Jam. I like living in my apartment with two other Pathway students and taking classes on campus. And I love shopping in LA!



### Walking on Sunshine

*Cathleen Small*

Sam Small finally decided it was high time he started walking.



### Fun for Grace with the Brownies

*Traci Cannon*



Grace enjoyed many field trips with her troop over her second grade year, including a visit to ARF, trick-or-treating at nursing homes, planting butterfly-attracting plants in Antioch, selling nuts and cookies, and enjoying a special father/daughter dance. A special thank you goes to Amber Silvis and Amy Sine, the troop leaders, for including Grace in this fantastic troop!



Grace Cannon, eight years old, is garbed in scrubs to tour John Muir Medical Center with her Brownie troop.

Below: Grace with the Brownie badges she has earned.



### Happy, with New Skills

*Christopher Lima*



Me, with Mom, Dad, and our dog, Abbey Lavern

My name is Christopher Lima. I am 17 years old and live with my mom and dad in Arcata, California (Humboldt County). I attend Arcata High School and am very active in Humboldt County Special Olympics.

After my mom and I went to the National Down Syndrome Congress Annual Convention last year in Denver, my mom thought I would benefit from the TalkTools® program. Although I have had years of therapy, often twice a week, I have no speech, was drinking out of a sippy cup, and was unable to blow a whistle, swallow pills, chew my food, or to distinguish between blowing and sucking.

In October of last year, my mom got in touch with Heather Peterson, and I began therapy with her. Heather did an evaluation and some training with my mom. She sent us home with a 20-minute-a-day, 5-days-a-week homework assignment. Within six months I no longer drank out of a sippy cup and am now an exclusive straw drinker! I'm able to keep food in my mouth while eating (very nice when we go out in public). I'm up to the fourth whistle on TalkTools®, and my mom is happy to say I can swallow a capsule. And I'm making lots of new sounds! My teachers and schoolmates are very impressed.

Once a month, Mom and I make the six hour trip to Danville to see Heather. We don't always get our five days in (more like three to four), but the results have been amazing. It certainly has improved my quality of life. Thank you, Heather!

## Teaching Hailey, Learning from Hailey

Logan Silliman

She huddles in a corner—facing the walls as though seeking shelter from the world around her. I continue my efforts to capture her attention. I have tried all my best tricks, surrendered to her many games of ring-around-the-rosy, and still cannot tempt her into the water without a struggle. There are good days and bad days with Hailey: days when she is happy to get in the pool for lessons and days when her sole wish is to be left alone, to avoid connection and narrow her world.

I finally entice her to the edge with a fish pool toy. I slide into the water while her attention is elsewhere and hold her hands as she jumps into my arms. I can barely contain my excitement when she emerges from the water with a shining grin. I praise her and hope she can comprehend how proud I am of her. I grasp that my efforts have had an effect and feel that I just might be making a difference for her—while I know for certain that Hailey is making a difference for me.

My swim coach selected me four years ago as a volunteer to teach swim lessons to Hailey, a nine-year-old girl diagnosed with both Autism and Down syndrome who is nonverbal, partially deaf, and unafraid of water (a dangerous mix of characteristics). This responsibility presents me with real challenges. My coach and Hailey’s family trust me with Hailey’s life. Hailey’s desire for independence and our lack of communication make safety, my primary concern, a struggle. I could not let her swim completely independent of me for safety reasons; however, it was unfair to Hailey to coddle her. Hailey’s determination makes her an individual not incapacitated by her disabilities and someone who requires my utmost respect.

I don’t come from a tradition where the line between childhood and adulthood is clearly marked and celebrated, but working with Hailey has marked a change in me. Working with Hailey means that fairy-tale endings are not the norm, that working



Logan and Hailey

hard does not guarantee success, and that life can be hard and cold and out of our control. Initially, I was disappointed in my seemingly failed efforts to help this girl learn to swim on her own; however, my disappointment was premature. When I focused on the joy and satisfaction that swimming brings Hailey, I was motivated to keep working. Meeting Hailey’s family has been inspiring. They handle her with care, perseverance, and tremendous patience. Their positivity allows them to manage the difficult times and to love Hailey unconditionally. Hailey’s family’s powerful optimism served as a great model. They inspired me to acquire that same fairness and patience toward Hailey and others in my life, which has greatly improved my work and my relationships.

Being an adult entails working to care for others or to impact others’ lives for the better, without any promise of benefits to your own life, while having the courage to handle responsibilities and to trust. Hailey taught me how to grow up, to let go of all self-interest, and to care solely for another person—allowing me to mature and experience love and success.



### Dynamic Duo

Kathy Harkins

This is how Adam Ferguson, (left), and Patrick Harkins do In-N-Out!

### Emma Heads to Work!

Monika Yungert



It’s official: Emma Yungert will be working two to three days a week at the California Academy of Sciences in Golden Gate Park, San Francisco. She has her employee ID and polo shirt and will attend three days of orientation before receiving her work schedule. She is very excited, and we are so proud of her.





### Friends and Graduates

**Teresa Sudmeier**

Sarah Sudmeier and Mariah Katz graduated from Castro Valley high school this year and will attend the Castro Valley transition program. Sarah and Mariah met at the Children’s hospital infant program, where they became friends.



### The High School Experience

**Donna Crawford**

T. J. Crawford graduated from Acalanes High School on June 13. We thank his teacher, Marie Townsend, and her wonderful aides for giving TJ a great high school experience. Congratulations, TJ, we are all so proud of you!

### Del Amigo Swim Program Makes a Splash

#### Katie Enjoys Del Amigo Swim Program

**Mimi Hsueh**

Katie Mack with her swim teacher, Allison, at Del Amigo pool.



#### Josias Learning to Swim with his Friends at Del Amigo

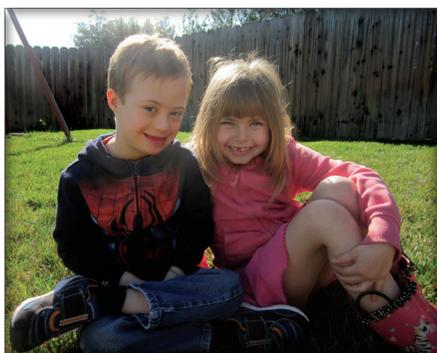
**Stephanie Segundo**

Josias takes a big step forward this summer, learning to swim at Del Amigo with his great instructor and making new friends.



### Special Friendship

**Laurie Hawley**



Liam and Laurel

One of my fears before Liam began kindergarten was that he wouldn’t make any friends. Special education staff had discouraged me from putting him in general education because he wouldn’t make any real friends—that the relationships with his peers would be unbalanced, with them just helping him.

Well, I am happy to share that Liam has just finished first grade, and this couldn’t be further from the truth! He has many balanced friendships. There are classmates who come over to our home for playdates and who invite him to their home for playdates. He has been invited to countless birthday parties. When I pick him up from school, kids often ask me if they can come over for a playdate with Liam soon. One boy even rattled off his phone number and asked if I could dial it and then put Liam on the phone to talk to him! These kids enjoy Liam as much as he enjoys them.

Liam has developed one extra-special friendship in particular—with Laurel. She was drawn to him at the beginning of kindergarten, and their friendship is still going strong. I got a text from another classmate’s mother this fall that read: “My son came home from school and said, ‘Mom, Laurel told me a secret, but I think I can tell you because she told the whole class. She is going to marry Liam.’” A few weeks later when Laurel was at our house for a playdate, she told me, “Laurie, when Liam and I get married, you are in charge of buying the pretty flowers.” This girl has warmed my heart on numerous occasions. One day when Liam

was absent, Laurel’s mom found a drawing of a broken heart and words saying, I miss, Liam, on her classwork. She missed him! She knows that Liam has some differences, but they don’t matter to her. A few months ago we were walking with Laurel into school, and I was encouraging Liam to hurry up. Laurel then says, “I know why Liam walks slower; it is because he has an extra rib from God.” She gets it. She may not know big words like chromosomes, but she gets it. I know she will be a special part of Liam’s life for years to come.

## A Day at the Races

Marianne Iversen

Thank you to Oak Tree Racing Association for their generous \$3,000 donation to the DSCBA. We were honored not only to receive the check, but also to ride a Clydesdale-drawn carriage onto the race track during the Alameda County Fair. Blair Hogan, Eli Cooper, and Adam Ferguson were part of the flag raising ceremony prior to the singing of the National Anthem. The Oak Tree Racing Association also treated us like VIP's for the day with lunch in the Directors Room and a finish line view of the races. Thank you, Oak Tree, for your support!



Above: Eli, Blair, and Adam



At right: Adam, Eli, and Blair raising the flag

At right: DSCBA gets a ride



At far right: A great day at the fair



## Thank You, Fastsigns



Special thanks to Wade Luckhardt from FASTSIGNS® in San Ramon for his continued generosity to the DSCBA!

## Wells Fargo Donates \$10,000 to DSCBA Program



Wells Fargo Foundation delivers a check for \$10,000 in support of DSCBA programs and services.

Thank you to Regina Gentry, Edward McElroy, and Mark Flower with Wells Fargo and to our beautiful members attending Baby & Me who joined in for the photo.

# For Your Time, Talent, and Treasures We Are Grateful...

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## HAPPY BIRTHDAY TO Ian Andrew Randick

Marlys Randick

## HAPPY BIRTHDAY TO The Twins

Mike and Karen Zolnier

## IN HONOR OF Caleb Adams

Ed Costa  
 Linda and Bill Watson

## IN HONOR OF Hailey Bornstein

Melissa and Ernie Bornstein

## IN HONOR OF Jamie Brewer

Betty Buckner

## IN HONOR OF Will Clark and in memory of Will's great-grandfather Walter Fanning

Susan Montague

## IN HONOR OF Samantha Copeland who is turning sweet sixteen

Debbie Copeland

## IN HONOR OF Madison Ferreira (Maddie Pie)

Malissa Oliveira

## IN HONOR OF Our grandson Brandon Garcia, who lights up our lives every time we see him

John and Judi Garcia

## IN HONOR OF Natalia Hazel, Wanbli Gleska and Joan Underbaggae

Amy Flynt

## IN HONOR OF Ben Hogan's Bar Mitzvah

Mindy Becker  
 Chris and Marie Legallet

## IN HONOR OF Blair "Midge" Hogan

Warren Collins  
 Mary Ann Hughes-Jones  
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## IN HONOR OF Granddaughter Katie Marie

Erika Walters and E. K. Buckman

## IN HONOR OF Cole Kelley

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## IN HONOR OF Eric Wells

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Chad Nitschke  
 The West Region AXIS PRO Team

## IN MEMORY OF Samuel's loving grandma, Susan Pollack

Eileen Nasto

## IN MEMORY OF Emily Poole

Dennis and Penny Whittaker

## IN SUPPORT OF Dance Classes

Nancy Scherbert

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Raymond, Lisa, and Chelsea Warner  
Thomas Wentling  
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Winchester Mystery House

Please know we work very hard to ensure your kindness is acknowledged. If your contribution to our success was received after the newsletter went to press, we will be honored to highlight your generosity in the next edition. Thank you!

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### World Down Syndrome Day Concord Lions Club

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Conner Anthony  
Katie Capone  
Madison Ferguson  
Taylor Fink  
Aparna Manocha  
Kristina Massa  
Kaitlyn Tran

## Shop... for the Down Syndrome Connection of the Bay Area

### Local Business Gives Back

Thank you to the following businesses that donated a portion of their proceeds from the Pirate Quest Street Fest on July 10, hosted by the Discover Danville Association.

### LAST DETAIL



130 E Prospect Ave.

consignit couture™

398 Hartz Ave.

Danville Jewelers

130 East Prospect Ave.

Rick's Picks

great deals everyday!  
375 Hartz Ave.

Christina's Fine Clothing



145 East Prospect Ave.

Cottage Jewel

100 E Prospect Ave.

DESIGN ELEMENTS



A special thank you to Board Secretary Judith Clark for "sharing her loot" at the Danville Pirate Quest Street Fest.

Please shop locally and support our community!

## Vehicle DONATION PROGRAM



The DSCBA has a vehicle donation program where you can donate your car, truck, van, motorcycle, RV or boat. A portion of the proceeds from the sale of the vehicle is given to the DSCBA for our programs and services.



All donations are eligible for a tax deduction; please talk to your tax advisor.



For more information or to donate your vehicle, please call 1-888-686-4483 or visit our website at [dsconnection.org](http://dsconnection.org)

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