



# MAKING THE Connection

THE DOWN SYNDROME CONNECTION OF THE BAY AREA NEWSLETTER • WINTER 2015-2016

## DSCBA 2015 Holiday Party

*Teresa Schaub*

The Down Syndrome Connection celebrated our 16th annual Holiday Party, held on Sunday, December 6. The Holiday Party continues to grow by leaps and bounds. As we celebrated, we welcomed many new families and enjoyed reuniting with countless friends and family.

Santa made his grand entrance early, in anticipation of all awaiting him, and the room was instantly filled with excitement and joy. The energy was truly amazing. This year Santa enjoyed participating in the bell choir, fabulously led by Nicole Patton.

*Holiday Party* → page 4





**Down Syndrome Connection  
OF THE BAY AREA**

101 J Town & Country Drive  
Danville, CA 94526  
Phone 925-362-8660  
[www.dsconnection.org](http://www.dsconnection.org)

**Making the Connection • Contents**

**DSCBA NEWS**

DSCBA Board and Staff	2
Jennifer Cooper Honored with June Downing Award	2
Executive Director's Message	3
Offering Opportunities to All Employees	3
Nancy LaBelle Awarded 2014 Employee of the Year	3
Gratitudes and Volunteers	19

**EVENTS**

Holiday Party	1, 4-5
2015 DSCBA Step Up Walk	6-8
Stepping Up Big Time	8
Gala for Giving Save the Date	17
World Down Syndrome Day	19
Annual Empowerment Forum	20
Upcoming Schedule of Events	20

**PROGRAMS**

Schedule (Programs) 2016 Connection Groups	9
Giving a Voice to Your Future	9
Aktion Club Takes Up a Collection	10
Benicia Step Celebrates Friendsgiving	10
Next Step Cooks Up Some Fun	10
Another Successful Summer in CRP	11
Down Syndrome Education Alliance Update	11
Eli Receives Self-Advocacy Award	11
Medical Outreach Alliance Update	12
Step In Celebrates Friendship	12
Small Steps Moos Their Way into Fun	13
Steppin' Up for Some Spooktakular Fun	13
Showing Off Their Artistic Talents	14
Step Out Welcomes the Fall	14
SF Step Rocks	14
Early Connections	15

**COMMUNITY SPOTLIGHT**

Josias' TK Photo	16
Katie Mack and Glacier	16
Welcome, Brayden	16
Opening Doors and Exceeding Expectations	16
Jonathan Learns to Text	16
Dream Come True	16
A Grandmother's Love Is Like No Other	17
Cooking Up a Healthy Life	17
Rock 'n' Roll Road Trip	17
Remembering Drew	18

**Board of Directors - 2016**

Isaiah Aguilar  
Paul Crawford, *Treasurer*  
Tom Delaplaine  
Andreas Dereschuk  
Martha Hogan  
Kendra Quintella, *Secretary*  
Janet Richman  
Eldeen Shields  
Alan Torres  
Mike Zolnier, *President*

**Board Meetings in 2016**

101 J Town & Country Drive  
Danville, 6:00-8:00 p.m.

The Board meets on the last Tuesday of the month. To attend or bring a guest, please contact the Board President, Mike Zolnier, at 925-819-1009 or [mike@vdbprop.com](mailto:mike@vdbprop.com).

(Note: dates can change so it's best to call before attending.)

**Advisory Board - 2016**

Natalie Hale, Reading and Handwriting Consultant  
Dr. Richard LaBelle, Psychologist  
Tim Lane, Attorney-at-law  
Nicole Patton, Music Therapist  
Maura Perkins, Past Board President  
Amein Punjani, Business Owner/Consultant  
Katherine Sefton, Developmental Therapist  
Julie Sodestrom, Past Board President  
Tracy Trotter, MD, Pediatrician

**Consultants**

Tempra Board, Grant Manager  
Jennifer Cooper, Director of Education  
Amana Hall-Jackson  
AAC Technology Assistant  
Judith Lunger Bergh, SLP  
Amy Parham  
Public Relations Manager  
Nicole Patton, Music Therapist  
Alice Pennes, Art Teacher  
Kshama Perera, Community Outreach and Events Coordinator  
Kati Skulski, SLP/AAC Specialist  
Michaela Sullivan, SLP  
Diane Viera, Reading Teacher  
Heather Vukelich, SLP/OPT

**Newsletter Staff**

Nancy LaBelle, Executive Editor  
Jen Kilian, Managing Editor  
Liana King, Designer

**Staff**

K. Leigh Alfrey, Assistant Small Steps Teacher  
Peggy Alreck-Anthony, Office Manager  
Catie Aznoe, Strategic Marketing Manager  
Laura Briggs, Teacher  
Eli Cooper, Ability Awareness Associate  
Susan Coulson, Teacher  
Marissa Erickson  
Community Outreach Associate  
Nancy Ferguson, Director, New Parent Support  
Rose Fruci, Membership Coordinator  
Amy Garcia  
Education Support Manager  
Marianne Iversen, Director of Programs and Adult Services  
Nancy LaBelle, Executive Director  
Christina Lewis, Teacher  
Scarlett McIntosh, Teacher  
Tamara Reed, Teacher  
Teresa Schaub, Community Outreach and Events Coordinator  
Cathleen Small, Medical Outreach and Government Affairs Coordinator  
Joseph Vaughn, Administrative Assistant

**Jennifer Cooper Honored with June Downing Award**

*Nancy LaBelle*



Jennifer Cooper was presented with the June Downing award at the TASH Conference in Portland, Oregon, on December 4, 2015. This award honors the important and courageous contributions of individuals who advance inclusive education and equitable opportunities for students, particularly those with disabilities and support needs. We are all very proud and so very fortunate to have Jennifer on our team at the DSCBA.

## Nancy's Notes

Nancy LaBelle, Executive Director



### Happy New Year, Everyone

Almost eight years ago, I was asked to take on the role of executive director of this amazing organization. I am honored to continue my role into 2016 with a very strong and hardworking staff and volunteer Board of Directors, who are all fully aligned in our mission. We are very fortunate to have, at the core of our success, donors who have given generously for many years and hundreds of volunteers. Aggressive outreach, the use of technology, the creation of strong partnerships in the community, and keeping to our objective of developing and sustaining measurable programs based on the needs of our community have all contributed to our growth and financial health.

To date we remain the only Bay Area organization serving the specific needs of people with Down syndrome of all ages and their families. We are also unique in that we offer a warm and inviting place to walk in or call in five days a week, eight hours a day, where we offer hope, education, community, and support. Daily, we welcome walk-ins and receive many calls from new families or from others who are caretakers of older children and adults with Down syndrome. Our support services have also proven to be very important for Bay Area education teams, hospital staff, extended family members, and other agencies.

It is an exciting time for the DSCBA as we are developing a short- and long-term strategic plan: a plan that will take us into the future fully understanding the need for

program growth and the infrastructure and revenue it will take to implement and sustain it. One of our challenges is to recruit new board members: those who will be excited about where we are going and all that we are accomplishing and who are passionate and well connected with the community, with the time and energy to work on important committees. If you know of someone, please refer them to Eldeen Shields, board member, via email at [ecshields@aol.com](mailto:ecshields@aol.com). Applications are being accepted now.

You do not have to have a child with Down syndrome to be on our board. Consider being part of our team!

Wishing you all a joyful and healthy New Year!

### Nancy LaBelle Awarded 2014 Employee of the Year

The Danville Area Chamber of Commerce designated DSCBA executive director Nancy LaBelle its 2014 Employee of the Year at its community awards event on April 28, 2015, at the Crow Canyon Country Club. More than 120 business professionals, government officials, town representatives, and other community members attended the afternoon event, sponsored by Chevron and Sutter Health, Palo Alto Medical Foundation. Dan Ashley, anchor of ABC7 News, served as master of ceremonies and presented the awards.

Chamber officials said, "Nancy's core belief is that everyone has the right to a voice, a good education, and to live the best life possible." This belief has been the driving force behind her personal success leading the DSCBA. She further elaborates by saying that she also knows that people with Down syndrome are often underestimated, and it gives her great joy to tell everyone about the abilities of all people.

Congratulations, Nancy!

### Offering Opportunities to All DSCBA Employees to Work Hard, Succeed, and Be Rewarded and Recognized Is at the Core of Who We Are

MEET FOUR OF OUR AMAZING EMPLOYEES

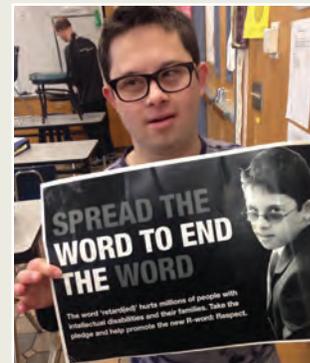


Above: **Joseph Vaughn, Administrative Assistant**

At right: **K. Leigh Alfrey, Assistant Small Steps Teacher**

Far right top: **Eli Cooper, Ability Awareness Associate**

Far right bottom: **Marissa Erickson, Community Outreach Associate**



Many enthusiastic participants, children and adults alike, joined Santa onstage, ringing in a few precious holiday melodies. All performers showed focus, quick hands, and great talent in helping create favorite and familiar songs while ringing multi-colored bells to their coordinating colored index cards—not an easy task! K. Leigh Alfrey once again graced the audience with a lovely clarinet performance. K. Leigh was accompanied onstage by her music teacher and her friend, Katrina. Adults and children of all ages enjoyed having a variety of desserts, playing games, and creating arts and crafts, including decorating (and eating) sugar cookies together.

We are thankful to all who attended. Special thanks to Diablo Valley Chapter of the National Charity League (NCL) for the variety of delicious desserts they provided. We appreciate Walnut Creek NCL for the darling gingerbread houses they decorated and for their volunteers who helped with the holiday party. To our many other friends and family who also helped to make the day successful, we say thank you!

We look forward to seeing everyone again in the new year!

*More Holiday photos* → page 5





# 2015 DSCBA Step Up Walk Raises \$150,00 Goal for Programs!

*Nancy LaBelle, Executive Director*



## Team Brandon G — Top Fundraising Team

It was a great day to picnic and to walk, promoting acceptance and celebrating inclusion at our Step Up for DS walk this year. Over 800 people attended the Step Up event, including 125 volunteers who contributed greatly to the day's success. A big thanks goes out to our Gold Event Sponsor, Macy's, and to Scott Ferguson, District Vice President, for bringing the Macy's team out to celebrate. Macy's generosity allowed us to offer the walk for free this year.



We ask everyone during National Down Syndrome Awareness Month to help us keep our vital programs and services going strong by fundraising for the walk. This year, 100 families created a fundraising page. Just by these families sending out an email, 1,622 generous people responded to the opportunity to give and raised over \$142,000 online—another reason we could offer the walk for free. Special thanks to the top four fundraising families who together raised over \$45,000: Team Brandon G—\$12,950, Team Mason Zolnier/VandenBerghe—\$11,625, Team Drucker—\$10,620, and Team Leah—\$10,150. We are not successful without everyone's help! Thank you to all the families who raised funds.



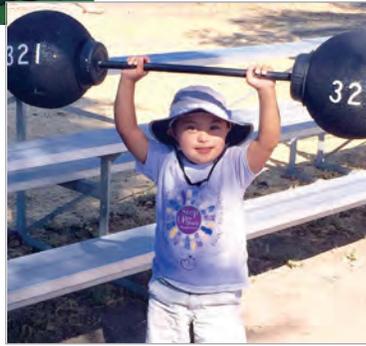
Our DSCBA staff outdid themselves once again this year to create a wonderful experience for all. We hope you enjoyed the new Pleasant Hill venue, where you could bring your tents and picnic lunch or choose from various food trucks. The carnival games and miniature golf were a big hit as well as the tattoos, the face painting, and the easier walk around the track. Many enjoyed the live music by Brand X and our awesome finish-line friends, such as the Golden Gate Garrison 501st Legion Star Wars gang and the West Coast Avenger superheroes. Thanks to Lisa Upton of Lisa Upton Photography for taking all the amazing team photos. Please see the thank you section on page 19 acknowledging more of our many generous volunteers.



We have received many positive reviews about the day, so we will be doing it again at the same location next year. Save the date: October 9. See you there!



Photos on pages 6 and 7:  
*An Affair to Remember Photography*  
and *Lisa Upton Photography*



More photos: DSCBA Step Up → page 8



DSCBA Step Up Walk photos: *An Affair to Remember Photography* and *Lisa Upton Photography*

## Stepping Up Big Time

*Colleen Tucker (Team Glam Grace)*

As I pulled into the parking lot with my husband and children, my sister came running up to our car, smiling. “The cutest little boy just came running up to me,” she said, “gave me a huge hug, and kissed me on the hand! You have to meet him—he is so adorable!” A few minutes later, I had a new friend, Josias. He kissed my hand, too!



**Aunt Colleen and Glam Grace**

This beautiful Sunday in October, I had the pleasure of participating in one of my favorite days of the year, Step Up for Down Syndrome. I am a proud aunt of 10-year-old Grace Cannon. Her team, Glam Grace, had nearly 30 people there to support our girl! The Step Up Walk is always such a fabulous day filled with family, friends, an overwhelming sense of community, and so much love!

Although I’ve enjoyed past events at Little Hills Ranch, I really like the event at Pleasant Hill Middle School. The new venue has everyone gathered around the infield of the track. It’s very cozy with all the groups around and kids running on the grass or playing the carnival games. They enjoyed the free popcorn and cotton candy. Some danced to the band’s music, while others got their face painted. All loved spinning any kind of prize wheel!

It’s hard to put into words how the Step Up Walk makes me feel: an abundance of joy and overflowing love all around! I cry (happy tears), I laugh, I chat with family and friends, and I always make sure I meet new fantastic people. We hung out with old friends and made new friends. Wow, our DSC community is inspiring: 1,000 incredible people, \$150,000!

I feel honored and truly blessed to be a part of this community. I am in awe of the amazing parents, siblings, grandparents, aunts, uncles, cousins, neighbors, and friends. The support systems these kids have are truly awesome. And how lucky we are to have these incredible, extra-chromosome teachers in our lives! Grace has taught me so much.

The community support that makes this day possible always blows me away. The numerous companies, the generous vendors, and the countless volunteers make my heart smile. One of many endearing things is the cheerleaders. The Carondelet Cougars brought so much happiness to so many. Grace high-fived every one of those beautiful young ladies! I hope they know how much they enriched the day. Thank you, ladies, for adding an extra special touch at the finish line.

The finish line. By far, my favorite part of every Step Up Walk. Sometimes, I don’t even walk; I just hang out at the finish line so I can hear Mike on the mic, cheering on our heroes. When our superstars reach the end, Mike yells out something like, “She got 20 out of 20 on her spelling test and can swim in the deep end independently! Let’s give it up for Grace Cannon!” There is pure elation on every face as they go under the balloon arch while cheerleaders and fans cheer and Mike enthusiastically shouts out accomplishments. The accomplishments include sitting like a rock star, learning ABCs, walking, reading, swimming, working at Kinder’s, graduating from Fresno State, and winning a gold medal at the Olympics. We hang out with some extremely cool people.

I am so moved every year at this event. The outpouring of love is staggering. You can feel it in the air! I am very grateful I had the pleasure of attending with my family. That Sunday in October was near perfect—the only thing missing was my buddy Eli doing karaoke! I’m already looking forward to next year.

## Giving a Voice to Your Future

Kati Skulski



We are so proud to announce yet another program at DSCBA: Future Connections! The goal of this program is for our participants, adolescents and young adults, to gain a confident voice by communicating what is important to them and how those important pieces are present in their lives. Thank you to the Disability Communication Fund (DCF) for the generous grant making this program possible.

Augmentative alternative communication (AAC) specialists Judith Lunger-Bergh, MA, CCC-SLP, Kati Skulski, MS, CCC-SLP, and Michaela Sullivan, MA, CCC-SLP, are working together to create a curriculum that supports adolescents and young adults in identifying their preferences, interests, and needs as they plan their futures. This is a crucial and often overlooked component of transitional and future planning.

The curriculum is based on the Framing A Future (FAF) tool, published by the esteemed Bridge School (<https://www.bridgeschool.org/transition/faf/index.php>) that specializes in providing education and best practices for users of AAC. FAF starts with a self-discovery survey of 65 items organized around seven major life areas: experiencing community membership, controlling personal health and welfare, pursuing lifelong learning, developing talents and interests,

creating healthy relationships, developing self-reliance, and developing a personal sense of spirituality. Multiple formats of FAF provide adaptations for users to accommodate visual, cognitive, and linguistic differences. FAF takes users through stages that address discovering 1) what is important to them, 2) how satisfied they are with benchmarks they consider important, 3) which areas are priorities for them, and 4) what steps need to be taken to accomplish their priorities. Future Connections' curriculum breaks down each life area into lessons using PowerPoint, videos, personal collages, music, and role-play to teach the concepts of the tool. After participating in the program, participants will have individualized digital and hard copy presentations reflecting their findings and opinions about the above-mentioned life areas. Various levels of technology and AAC will be utilized by the participants to participate in, create, and present their future wants and needs. These presentations will be invaluable in empowering our young teens and adolescents to advocate for themselves in their home, school, and professional lives.

We anticipate starting a Future Connections group in the new year. If you are interested, please contact Kati at [kaskulski@gmail.com](mailto:kaskulski@gmail.com).

### 2016 Winter-Spring Schedule of DSCBA Classes and Connection Groups

#### Danville Location Classes

**Music Therapy**

Ages 0–3 years: 9:00–10:30 a.m.  
 Ages 4–7 years: 10:45 a.m.–12:15 p.m.  
 Jan. 9, Feb. 13, Mar. 5, Apr. 2, May 7, Jun. 4

**Small Steps**

**Monday:** 3:30–5:00 p.m.  
 Session 1: Jan. 4, 11, 25, Feb. 1, 8  
 (No class Jan. 18)  
 Session 2: Feb. 22, 29, Mar. 7, 14, 21, 28  
 Session 3: Apr. 11, 18, 25, May 2, 9, 16

**Steppin' Up**

**Wednesday:** 4:00–5:30 p.m.  
 Session 1: Jan. 6, 13, 20, 27, Feb. 3, 10  
 Session 2: Feb. 24, Mar. 2, 9, 16, 23, 30  
 Session 3: Apr. 13, 20, 27, May 4, 11, 18

**Next Step**

**Tuesday:** 4:00–5:30 p.m.  
 Session 1: Jan. 5, 12, 19, 26, Feb. 2, 9  
 Session 2: Feb. 23, Mar. 1, 8, 15, 22, 29  
 Session 3: Apr. 12, 19, 26, May 3, 10, 17

**Step In**

**Thursday:** 4:00–5:30 p.m.  
 Session 1: Jan. 7, 14, 21, 28, Feb. 4, 11  
 Session 2: Feb. 25, Mar. 3, 10, 17, 24, 31  
 Session 3: Apr. 14, 21, 28, May 5, 12, 19

#### Adult Classes throughout the Bay Area

**SF Step (San Francisco)**

**Tuesday:** 4:00–5:30 p.m.  
 Session 1: Jan. 5, 12, 19, 26, Feb. 2, 9  
 Session 2: Feb. 23, Mar. 1, 8, 15, 22, 29  
 Session 3: Apr. 12, 19, 26, May 3, 10, 17

**Step Out (Oakland)**

**Wednesday:** 4:00–5:30 p.m.  
 Session 1: Jan. 6, 13, 20, 27, Feb. 3, 10  
 Session 2: Feb. 24, Mar. 2, 9, 16, 23, 30  
 Session 3: Apr. 13, 20, 27, May 4, 11, 18

**Benicia Step**

**Wednesday:** 4:00–5:30 p.m.  
 Session 1: Jan. 6, 13, 20, 27, Feb. 3, 10  
 Session 2: Feb. 24, Mar. 2, 9, 16, 23, 30  
 Session 3: Apr. 13, 20, 27, May 4, 11, 18

**For information about the classes or to RSVP before meetings**

Contact Marianne Iversen at 925-362-8660 or email [DSCBA@dsconnection.org](mailto:DSCBA@dsconnection.org)

**For more information check the DSCBA website**

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

#### CONNECTION GROUPS

**Early Connections**

For parents and their babies (infant to three years old with Down syndrome)  
**Facilitator:** Nancy Ferguson  
**Location:** DSCBA, Danville  
**Wednesday:** 10:30 a.m.–12:00 p.m.  
 Jan. 6, Feb. 3, Mar. 2, Apr. 6, May 4, Jun. 1  
**Saturday:** 9:30–11:00 a.m.  
 Jan. 23, Feb. 20, Mar. 19, Apr. 16, May 21, Jun. 18

**Parents with School-Aged Children**

**Facilitator:** Laurie Hawley  
**Location:** DSCBA, Danville  
**Wednesday:** 7:00–9:00 p.m.  
 Feb. 10, Mar. 2, Apr. 13, May 4, Sep. 7, Oct. 5, Nov. 2

**Grandparents**

**Facilitator:** Martha Hogan  
**Location:** DSCBA, Danville  
**Wednesday:** 10:00–11:30 a.m.  
**4th Wednesday of every month:** Jan. 27, Feb. 24, Mar. 23, Apr. 27, May 25, Jun. 22

**Families of Maturing Adults**

For caregivers of someone with Down syndrome and signs of Alzheimer's disease. In collaboration with the Alzheimer's Association.  
**Location:** Alzheimer's Association  
 3657 Mt. Diablo Blvd., #250, Lafayette, CA  
**Wednesday:** 1:00–2:30 p.m.  
**3rd Thursday, quarterly:** Jan. 21, Apr. 21, Jul. 21, Oct. 20

## Aktion Club Happenings

Marianne Iversen

The Aktion club has been collecting travel-size toiletries to give to the Blue Star Moms for shipment to military personnel around the globe. Some of the Aktion club members attended the Kiwanis luncheon in November to present the toiletries to Catharine

Baker, Assemblywoman, 16th Assembly District. The Aktion club members were delighted to learn that their collections will be part of the many care packages sent out for the holidays.



Aktion club members celebrated their year-end with a holiday party and gift exchange at Melo's Pizza & Pasta

## Benicia Step Celebrates Friendsgiving

Tamara Reed

The Benicia Step group held their annual fall taco night in October. This group loves to cook and entertain together; in the spring they will be putting together their own cook-book with recipes they've used many times and perfected over the years. In November, they made a wonderful Thanksgiving feast and celebrated Friendsgiving together.



## Next Step Cooks Up Some Fun

Marianne Iversen

The Next Step class was fortunate to have Dianna Woodbury from Cooking Buddy join us for a few weeks. She taught the class about using healthy ingredients while making some delicious food. We learned what a serving size should be by tracing around our hands and circling our palm section. We practiced putting our eating utensils down between bites so that we could actually enjoy our food, as well as letting it digest. We had secret ingredients in a couple of the meals we made to show how easy and tasty it is to put vegetables in our diet; the spaghetti-squash mac and cheese was a favorite.

Many thanks to the San Ramon Valley Kiwanis for the generous grant that allowed us to purchase cooking equipment and to have Cooking Buddy join us this year. We look forward to continuing to add cooking to our classes as another form of learning and fun in all of our classes.

At right, clockwise:

Emma Tippet, enjoying the food preparation

The group, ready to cook

Vikram Ramiya preps the spaghetti squash

Christian James and volunteer Bailey DeSchane





## DSEA Update

*Jennifer Cooper, Director of Education*

Though it is now wintertime as you read this update, I am writing it in my favorite season, autumn. I love autumn: leaves of color, crisp air, and a sense of change and celebration on the horizon. And because that's what's on my mind today, that will be how I think about the

Down Syndrome Education Alliance update for this edition. Just for fun.

Point one: have fun! It's easy to lose sight of fun when you're in the thick of therapies, medical concerns, Individual Education Plan (IEP) navigation, unmet goals, and contention between home and school (not that those things are always present). Thankfully, I witness many moments of fun between parents and their children, educators and their students, and all our staff at the DSC. It's tough to continue what we all need to do without finding and feeling the joy. Fun is necessary to allow us to keep going, reduce stress, and replenish as we continue to find solutions and work for the best outcomes for our children. Just as that fun spirit is good for adults, it's equally important for our children's education. Yes, education. Research suggests that fun isn't just beneficial to learning, but is actually a required element of authentic generalization, memory, and learning.

The colored leaves of fall remind me to mix it up. Point two: mix up the modes, the approaches, and the people involved in your student's learning. You certainly don't want to get rid of working strategies, but it's always good to make sure that students can begin to consolidate information and to generalize to more than one approach. The DSEA has been mixing it up by adding more staff (welcome to Amy Garcia, Education Support Manager) and reevaluating our priorities and how to best meet the diverse needs of families and educators.

I love those cold crisp days where I can see across the Bay for miles—such clear vision. Point three: think about the vision for your student. Isolated goals are just that, isolated. Make sure that the goals are within a context of the big picture. Is your student getting ready to transition to middle school or exit high school? Do you need goals that increase the fun you can have? For example, can you go to a restaurant with your child or out to a large venue? Perhaps an attentional or sensory goal is in order. Is your child participating in class, e.g., communicating, raising their hand, sitting at circle, being a part of the classroom community? It's about a lot more than two plus two and saying CVC (consonant-vowel-consonant) words.

Finally, celebrate the successes, big or small. Coming in from the playground in an orderly and timely fashion or reading their first book—celebrate! Positive reinforcement is beneficial not only for your student, but for the adults in our children's lives. We all work hard; rewards, reinforcements, and acknowledgements help us continue to move forward. The DSEA is celebrating an active season in which we held a class for parents called Setting the Stage for Success at the beginning of the school year; several DS 101 trainings for both parents and educators; ability awareness trainings and consults; a Numicon training; one-on-one consults with individual educators; and of course, many hours helping families with the IEP process. We are celebrating the growth of the DSEA. There are hundreds more things we want to do (just like there are always many more goals to try to craft), but we can also pause and realize *we're making a difference*.

## Eli Receives Self-Advocacy Award

*Marianne Iversen*

DSCBA staff member Eli Cooper received the Carlos Quintong Award for Self-Advocacy on October 23, 2015, at the Ed Roberts Campus in Berkeley. He was nominated for his extensive work with our ability awareness presentations. Eli shares awareness and acceptance about Down syndrome while especially focusing on the campaign to Spread the Word to End the Word. We are so proud of all of Eli's hard work and self-advocacy!



## Another Successful Summer in CRP

*Marianne Iversen*



Top photo: The Kangas. Second photo: The Roos

This summer's seven-week Communication Readiness Program was a huge success. The children, ranging in age from three to seven, were divided into two classes: the Kangas, which included eight children going into kindergarten through second grade, and the Roos, which included seven children going into preschool or transitional kindergarten. The changes that we saw in the 15 children included increased verbalization for those students who are verbal and an increased use of Augmentative Alternative Communication (AAC) by students who are nonverbal. Social and school readiness skills were shown to be improved along with an increase in fine motor, literacy, and independence skills.

An important component of this program is the follow-up with each child's fall school team, which provides them with a transition binder of recommendations and assessments. The school teams have been very receptive to collaborating with us to ensure the best possible education and methodology to help meet each child's individual needs. Feedback about the program from parents, staff, and volunteers was overwhelmingly positive, and we are so proud that we were able to provide this valuable program for the third year.

## Medical Outreach Alliance Update

*Cathleen Small*



At events such as this one for NASA at Moffett Field, we get to share information and bring awareness to our community, while doing some fundraising, too!

It's been a busy few months in the medical outreach and legislative advocacy worlds! We recently finalized our Conversations about Down Syndrome presentation, which we'll be delivering to nurses, social workers, and budding genetic counselors in the upcoming months. This hour-long presentation will inform persons in the medical field about general facts and myths about Down syndrome, resources for new parents and families, and how to discuss the topics that will likely come up as they work with these new families.

On a related note, I've been participating in a government affairs committee for Californians who are committed to supporting legislation that will benefit people with Down syndrome. My main focus at this moment is in getting a Down Syndrome Information bill into the legislature. This bill, which has been passed in fourteen states and counting, would ensure that all families receiving a Down syndrome diagnosis (either prenatally or at/after birth) are given accurate, up-to-date, medically backed, unbiased information about Down syndrome. It is no secret that the resources shared with new parents and the materials given vary widely, depending on where and from whom the parents receive a diagnosis. Many are given outdated or biased information, and the passage of a Down Syndrome Information bill would ensure that doesn't happen in the future.

However, as part of the government affairs committee, I've also been fortunate enough to participate in some of the work toward the passage of the ABLE (Achieving a Better Life Experience) Act, which is so important for people with Down syndrome and other disabilities. And this year, we're hoping to work toward offering more post-secondary options to teens and young adults with Down syndrome. It's such an exciting opportunity to be able to work toward things that will benefit our members (and of course my own son!) in the future.

And in my spare time (ha!), I've been participating in the Combined Federal Campaign on behalf of DSCBA. The primary goal of the campaign is to raise funds for nonprofits such as ours, but an added bonus is the chance to bring more awareness to our community. At all of these events I've attended, I've been able to talk to people about Down syndrome and share stories of our community, which is very rewarding.

The 2016 year looks to be an exciting one for us, both in medical outreach and in our grassroots advocacy and legislative efforts!

## Step In Celebrates Friendship

*Tamara Reed*

Step In has had a great fall session. Our first week back, we said goodbye to longtime volunteer Lauren Reed and wished her well in her new endeavors. In October we headed to the bowling alley. What a fun party it was! Stacey bowled her best score yet—179. Yes, that happened! We applauded each strike and spare as she kept them coming. In the following weeks, we started cooking together. The group made some great desserts and even a main course for a Friendsgiving feast. We concentrated on healthy foods and gluten-free recipes.

From the top: J.R. Dantes, K. Leigh Alfrey, and Stacey Elliott working on final touches of their Friendsgiving feast

Step In cheers their friendship

Party time at the bowling alley

Joseph Vaughn, J.R. Dantes, and Nicole Hodsdon set the table



## Small Steps Moos Their Way into Some Fun

Susan Coulson

We have such a fun and wonderful time here at Small Steps. Each week we have our hello song where everyone sits and welcomes each other. Then we're off dancing to the "Wake Up" song. After that, we move on to different art projects each week: painting fall trees using our arm for the trunk and fingers for the leaves, making cow hand puppets out of socks (that was a favorite), making Jell-O and gummy bears cups—all involving lots of messy play. The children love getting into our circle for the "Merry-Go-Round" song for their favorite moves. We have an exciting obstacle course where the children can climb, slide, go through tunnels, walk the balance beam, wobble on the wobble board, and jump on the trampoline. The children navigate the obstacle course during the book reading. We read *How To Speak Moo!* during this past session. At the particular obstacles, we integrate the words out of the book with the child as it's being read—for example, jumping on the trampoline we say moo moo. At the last obstacle, in our rowing boat, they sing "Moo Moo" while everyone joins in with a musical instrument for the exciting ending to the book. We end our fun with a good-bye song and then either hop or jump and sing to meet our family.



Above: Vivian Vernay rowing her boat  
Top photo: Lucas Paterno and Will Drucker rowing their boat



Above: Avery Gordon going through the tunnel  
Top photo: Katie Mack with the trampoline

## Steppin' Up for Some "Spooktacular" Fun

Laura Briggs

Steppin' Up had a "spooktacular" time this Halloween! In addition to our annual Halloween Movie Fest, we cooked homemade pumpkin tarts. After walking to the nearby Lucky store to buy our ingredients, we unrolled and cut the dough into rectangles. Then we used small cookie cutter shapes to make a jack-o'-lantern face on one rectangle. After putting some pumpkin filling on another rectangle of dough, we topped it with a jack-o'-lantern face and then used a fork to seal the tarts. After baking it was time to eat! The students said the following about this experience.

*Jonah:* I liked to eat it.

*Roan:* I liked shopping.

*Gabriel:* I like to eat!

*Vincent:* I liked making them and eating the frosting.

*Rohan:* I liked doing the shopping and eating the Pop-Tart.

*Michael:* I liked making the faces.

Lauren really enjoyed the shopping. Nina also enjoyed the shopping trip because it was her birthday, and the woman in the bakery gave us cookies and sang "Happy Birthday" to her.

It was a great time all around.

Top: Gabe Rettig mixing the pumpkin and Rohan Bhupatiraju unrolling the dough

Center: Pumpkin tarts

Bottom: Camille Hunt, Vinzant Cruzat, and Jonah Zimmerman-Bloch





We'll be closing up the year with a relationship training series facilitated by Sharon Potter. It has created fodder for the group to be vulnerable while also fostering empowerment and agency over their own bodies. As always, we danced our hearts out and reveled in the good vibes our community continues to build. To end 2015 we will sample treats from Sweet Bar Bakery, our favorite spot in the neighborhood.

Top: Athena Sjoberg with her completed art project

Right: Step Out enjoys their time at Sweet Bar Bakery

## Step Out Welcomes the Fall

Scarlett McIntosh

Step Out Oakland has been welcoming the fall season and the changing leaves with conversations about person-centered-planning. One way that we initiated these conversations was by creating Wellness Wheels facilitated by art instructor Alice Pennes. We also spent time discussing areas of our lives we feel we have a sense of control over and areas where we would like to feel more control. Many group members expressed long-term desires to live on their own and get better at managing their own finances and schedules. Our group talked about tools we can utilize to achieve those dreams and timelines that fit our individual strengths. Additionally, we talked about community and specifically interdependence as a way to support others and get support.



## SF STEP ROCKS

Christina Lewis

This past year, SF Step had the pleasure of receiving free instruments from Little Kids Rock. This allowed us to create our very own rock band that we have named SF STEP ROCKS! We love to play along to our favorite CDs from Glee and Frozen, as well as Britney Spears and Taylor Swift.

Left: Emma Darby rocks out on guitar

Right: Emma Yungert enjoys her time on the keyboard



Above right: Christopher Vidales shows his talents on a drum set

## Showing Off Their Artistic Talents

Marianne Iversen

Art instructor Alice Pennes recently worked at the Step In program assisting the students in creating mosaic houses. First the students chose their background colors to paint and then were given pieces of paper shapes to "build" their houses. They picked from winter or holiday themed color schemes and had a wonderful time creating their masterpieces. A collage of these delightful pieces will be created and hung at the DSCBA.

Many thanks to Sydney Stern Memorial Trust, CARH, and the Alice Beckman Fund for supporting our art program and allowing us to provide this critical means of encouraging creativity, imagination, and self-expression.



Step In shows us their beautiful houses

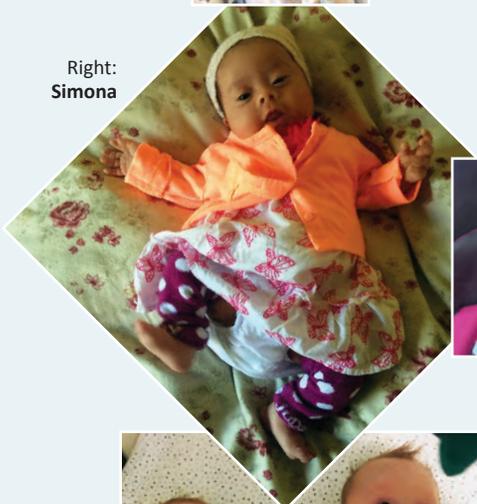
## Early Connections

*Nancy Ferguson*



Right:  
Brayden

**Welcome to  
Some of Our  
Newest Members**



Right:  
Simona

Below:  
Emma



Right:  
Alec and  
Owen



Above: Annika



Above: Jordan



Above: September Early Connections

**Connecting Families  
Together Is What  
We Love To Do!**



Right:  
Nancy Ferguson  
visiting Annika



Right:  
Dominic  
and Olivia



At right  
and  
above:  
Ready  
to meet  
Santa



*Scheduling information for Early Connections is on page 9.*



### Jonathan Learns to Text

Gail Ewell

One day as I'm sitting in my room, I hear my phone getting text messages. I know my daughter is not here; who is this saying "hi mom," "hi mom"? I look in on my son, Jonathan, and realize it's him! OMG!

Jonathan learns to text independently

Much to my surprise, he used his iPad and iMessage on Quick Talk AAC\* to text me. Wow! Jonathan is primarily non-verbal and uses Quick Talk AAC to communicate his needs.

Then my daughter comes home and says (in her irritated voice), "Jonathan is texting my friends!" Ha-ha—I'm so happy at his new skill (she's mad).

My son loves to text and to take selfies. It's a way to be connected. Sometimes he just repeats text, other times he answers—but either way it's awesome.

My husband, with friends, developed the software as a less expensive option for AAC. We are happy he did.

\*Quick Talk AAC by Digital Scribbler, Inc, <https://appsto.re/us/7X5eD.i>

### Josias' TK Photo

Stephanie Segundo



Josias Ellis, enjoying transitional kindergarten

### Welcome, Brayden

Maria Shtulman

Brad, Maria, and big sister Kylie are excited to announce the arrival of Brayden Tyler Shtulman. He was born September 18, 2015, at 11:04 p.m., weighing 7 pounds 13 ounces and measuring 20¼ inches long.



### Opening Doors and Exceeding Expectations

Katie Drucker



Will went on a field trip to the Danville public library with his class. Here, he is holding his own library card, which he received that day along with all his classmates.

Will Drucker started kindergarten at San Ramon Valley Christian Academy (SRVCA) in August. He is the first child to attend SRVCA with Down syndrome or any significant resource needs. He is in Ms. Patton's class with 14 kids, with an aide to help him stay on task.

Will quickly bonded with his peers as well as the kids in the other grades. When he gets dropped off at school in the morning, typically there is a group of older boys anxiously waiting to play with him. Often a group of about 25 kids of all ages plays duck-duck-goose or tag before starting classes. Will also is enjoying many playdates with his friends.

Will just completed the first quarter and met or exceeded every academic mark on his report card. Each week he memorizes scripture, rhymes, and sight words. He's even assisted his classmates with their sight words when they don't know them. His family could not be more proud of him and all his hard work. It is great to see inclusion working so beautifully for Will and the other kids, too.

### Dream Come True

Susana Barajas

Elisa Faith Barajas is a junior at Fred C. Beyer High School in Modesto, California. Elisa has been in a fully inclusive setting since second grade. She has done amazingly, largely due to her supportive general education peers who have consistently helped Elisa feel more like them than different.



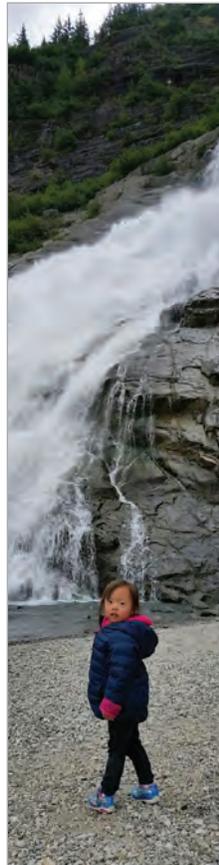
This October, Elisa was invited to cheer with the Beyer Varsity Cheerleaders at a football game between the Modesto High Panthers and the Beyer Patriots! She was able to practice with the varsity squad several times before the game. The girls were so sincerely supportive and took Elisa under their care to make sure she had the routine down before the big event. The night of the event was a dream come true for a lovely young lady who continues to amaze us with her perseverance and determination to be just like everyone else!

Elisa Faith Barajas, part of the squad



### Katie Mack and Glacier

Mimi Hsueh



Katie Mack, enjoying Nugget Falls, Mendenhall Glacier in Juneau, Alaska



Families ♦ Births ♦ Seniors ♦ Professionals

*An affair to remember photography*

Don't let your important moments fade  
Instead, let me preserve them

Mention this ad and get 10%  
off your scheduled session

925-565-6074

[www.anaffairtorememberphotography.com](http://www.anaffairtorememberphotography.com)

[www.facebook.com/anaffairtorememberphotographyvoldwell](http://www.facebook.com/anaffairtorememberphotographyvoldwell)

### A Grandmother's Love Is Like No Other



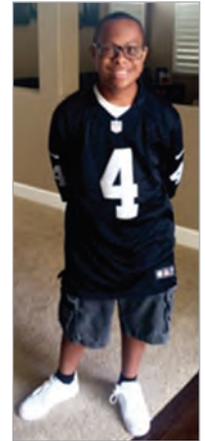
No matter if you call them Grandma or Yaya, they are always there for you. They want you to be happy. They are ready to give and receive hugs—just like you—24/7! They cherish the beautiful person you, Tatiana, have become.

### Cooking Up a Healthy Life

Lanette Gresham

My amazing son, Israel, is 16 years old and aspires to be a chef. He understands the importance of healthy eating, drinking water, eating fruits and veggies, and limiting sugar, as well as the difference between protein and calcium.

His goals in life are his decisions. I'm just allowing him to be who he is and live his life to the fullest. I'm his biggest advocate and fan.



### Rock 'n' Roll Road Trip

Jennifer and Eli Cooper



Above: Eli rocks the washboard  
Left: In front of the Rock and Roll Hall of Fame.

**Mom's story:** Eli and I took a 22-day "Rock 'n' Roll Road Trip" as a celebration of his high school graduation. We logged 2,722 miles, 9 states, 20 cities, and countless live music performances and music history venues. The experience was one that left lasting imprints of joyous, funny moments with my boy, the open minds and hearts of most of whom we encountered, and the way that music is a common fabric that can seamlessly weave in such diversity. What a celebration!

**Eli's story:** I took a road trip with my mom last month and went to Chicago, Detroit, Cleveland, Louisville, Mississippi Delta, New Orleans, Houston, Austin, and home.

I thought that my college should be on the road. My highlights would be the Rock Hall of Fame in Cleveland and being with my mom. I would so recommend this to people because WHO DOES NOT WANT TO BE WITH THERE MOM ON A ROAD TRIP WHO WHO WHO WHO WHO—NOBODY!

2016

# Gala for Giving

To Benefit  
The Down Syndrome Connection  
of the Bay Area

Join us for "*Midnight in Paris*"  
An elegant evening of fine dining,  
auctions, dancing, and amazing stories.

*Ooh La La!!!*

Saturday, May 21<sup>st</sup>, 5:30pm - 11:00pm  
Diablo Country Club  
1700 Club House Road, Diablo, CA

**Reserve your seat today!**

Go online to  
[dsconnection.org/gala](http://dsconnection.org/gala)

To donate an item for the auction, please email  
[events@dsconnection.org](mailto:events@dsconnection.org)

## Remembering Drew

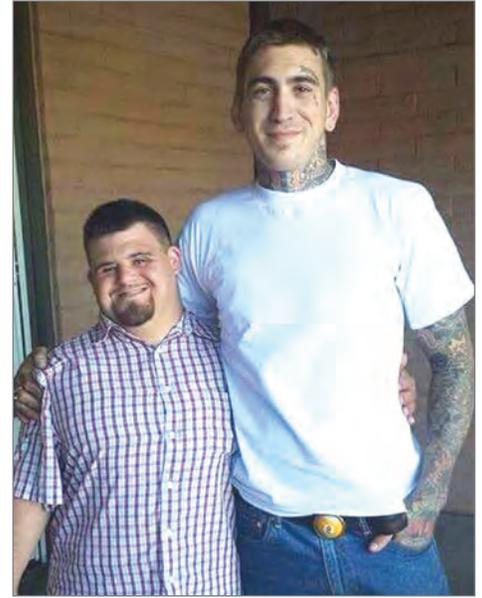
*The Spina Family*

Drew Cambra began volunteering at the Connection when he was a skinny thirteen-year-old with blue hair and a wise serenity that contradicted his outward persona as a mischievous middle school kid. He had a sweetness that grew from his deeply empathetic soul, but he had no idea he was special. Before he came to the Connection, he had met a little girl with Down syndrome at school and became close friends with her. This friendship continued into middle school. When he heard about the Connection and realized there was a place he could volunteer, he brought his mom Eleisa there, and they both became a ubiquitous presence at Step classes and all events.

Our family became close to Drew and Eleisa during those years. My son, Julian, became especially close to Drew. Julian was a wild little boy whose behavior could be described as challenging. But with Drew, he

was calm and focused. He emulated him like a big brother and tried to do whatever Drew did. Even during the years we lost contact with Drew and Eleisa, Julian continued to speak about his brother Drew. Recently, when we got back in touch with Drew, Julian called and texted him frequently. As heartbreaking as losing Drew was for our family, for Julian it has been by far the hardest loss he has ever had to live through. Drew had a quiet way of connecting that was unique and unusual in a beautiful way.

Drew found his niche as a Pal (peer class volunteer) working with teens and young adults in the Step classes taught by Nancy Henderson, one of the original teachers. Drew didn't think of himself as a volunteer, but truly as a pal, a peer. When he won a volunteer award, he told the audience simply, "I love being with them" and acknowledged each of his friends by name.



Julian Spina (left) and Drew Cambra



*Drawn to Drew*

*A young man with an old soul came to work with us one day.  
His gift that filled a hole was his ability to play.  
The easy, quick connection forged with all the folks he met,  
Made Drew, upon reflection, our most valued resource yet.*



*It's rare to find a young peer who just gets our population.  
A youth who will incline his ear to end discrimination.  
He offered friendship to some teens who had a learning difference.  
He simply wanted to have fun while tearing down the fences.*



*He made so many friends, our Drew, and garnered our affection.  
His ears had gauges, hair was blue; he chose his own direction.  
His heart was gold, and now he's gone; his shining light's within us.  
Safe passage, Drew, for you we mourn. Your spirit lives among us.*



*In loving memory,  
Nancy Henderson  
Former teacher at the Down Syndrome Connection  
11/26/2015*



A poem written by Nancy Henderson



## Upcoming Schedule of Events

**Saturday, February 6, 2016**

**ANNUAL EMPOWERMENT FORUM** (see below)

- Health and Wellness, A Lifelong Journey

**Sunday, March 20, 2016**

**WORLD DOWN SYNDROME DAY** (see page 19)

- Let's all play at Matteo's Dream Park

**Saturday, May 21, 2016**

**Gala for Giving** (see page 17)

- Midnight in Paris

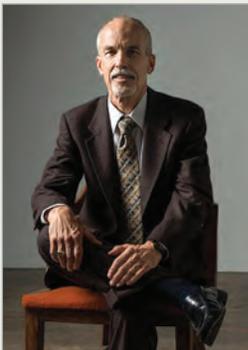
For details — [dsconnection.org/gala](http://dsconnection.org/gala)

# 2016 DSCBA ANNUAL EMPOWERMENT FORUM

**February 6, 2016** at San Ramon Roundhouse Conference Center

**KEYNOTE** "Health & Wellness, a Lifelong Journey" with Author Dennis McGuire, Ph.D

**BREAKOUTS** Topics for all ages including: General Health Concerns; Health & Nutrition; Common Behaviors; Sexuality & Safety; Reasons for a Developmental Pediatrician; Dual Diagnosis; and Mental Health



**Speakers:** Dr. Tracy Trotter, Dr. Ann Parker, Dr. Lucia Milburn and other panel experts

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

Dennis McGuire is a consultant in private practice and is the former Director of Psychosocial Services for the Adult Down Syndrome Center of Lutheran General Hospitals in Chicago. Dr. McGuire helped to establish the Adult Down Syndrome Center which has served the health and psychosocial needs of over 500 adults with Down syndrome since its inception in 1992. He has published numerous articles and coauthored two books "Mental Wellness in Adults with Down Syndrome" and "The Guide to Good Health for Teens and Adults with Down Syndrome."