



Making the

Connection

DOWN SYNDROME CONNECTION OF THE BAY AREA

WINTER 2012-2013

- Community News
- Events
- Programs
- Education

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A Holiday Party to Remember

Kathy Harkins

It was a blustery day, as Winnie the Pooh would say. But that didn't stop Santa, his elves, or the partygoers from attending the DSCBA's 13th Annual Holiday Party. We set up Friday night at Los

Cerros thanks to Mike Cannon, Gloria Delrio-Casadont, Megan Portoni, Theresa and Hannah Dillon, and Cristyn Carlson. Setup included hanging fabulous handmade decorations created by the

Brownie Troop from Sequoia Elementary School in Pleasant Hill. For the raffle, we proudly displayed gingerbread houses made by Marian Cathedral-King (from Chevron) and her family, Macee LeMoine, and

Danyella Duran. The NCL chapters from Rolling Hills and Diablo Valley came loaded with treats and volunteers. With help from the Dougherty Valley High

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Continued from page 1

School cheerleaders and other friends of the Connection, the day was magical! The bell choir played seven holiday songs and was led by Music Therapist

Nicole Patton—truly something to watch and hear! Santa arrived and visited with everyone. He took copious notes of what each person was wishing for Christ-

mas. K. Leigh Alfrey delighted us once again with a clarinet performance, and everyone enjoyed the fun craft activities. Folks visited with old friends, and new friends

were made. Many thanks to my partner in crime, Nancy Ferguson, for helping me put together a great event. It is truly a magical season!





Holiday party photos: Lisa Upton of Lisa Upton Photography

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Down Syndrome Connection OF THE BAY AREA

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Board Meetings – 2013

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

The Board meets on the 3rd Tuesday of the month: February 19, March 19, April 16, May 21, June 18, July 16, August 20, September 17, October 15, November 19. No December meeting. To attend or bring a guest please call the Board President, Terese Ghilarducci at 925-872-5858 or e-mail her at teresemarieg@comcast.net.

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Nancy's Notes

Nancy LaBelle, Executive Director



Happy New Year, and thank you all for your support in 2012.

Because of generous grantors, committed members and their giving families and friends, our energetic volunteers, a welcoming local community, a dedicated and compassionate staff and board of directors, we surpassed our budget goals in 2012.

When financial support continues, it tells me that we are achieving the goals our funders want to support and our community appreciates and needs. Only when we meet our financial goals are we able to sustain vital programs and welcome growth without risk to operations. I'm happy to say that with everyone's generosity in 2012, we created new programs and were able to hire staff to support them.

One new program is the Down Syndrome Educational Alliance (DSEA). In 4 short months, this alliance has 20 Down Syndrome Specialists in 20 Bay Area public and private schools. One program goal is to inform educators on the importance of a rich education based on individual developmental strengths. We will also provide the tools to teach all school-aged children with Down syndrome to their fullest potential. We are grateful for the Down Syndrome Global Foundation and our families who have financially supported getting this program off the ground at our Gala Fund-a-Need auction.

My personal goal for the DSEA program is to make a significant impact on learned independence, ultimately opening doors for enriching employment and living opportunities as children with Down syndrome prepare to leave school. From what I have learned in my five years at the DSCBA, is that this rich education experience cannot be accomplished without a strong, well thought-out communication system, from preschool age on.

To meet this challenge in 2013, I will be joining our Expression Connection project (the Augmentative and Alternative Communication (AAC) program) with our Educational Alliance program to offer teachers the education and total communication systems needed in the classroom that will set up our students for success.

One thing we know for sure: Behavior is communication! We are seeing children change negative behaviors when given a way to communicate their needs. As you know, because of speech delays, low muscle tone, and in some cases, Apraxia, speech therapy alone may not get children, teens, and even adults with Down syndrome expressing their needs. Thanks to a grant from the California Communications Access Foundation, we have 20 families who have taken advantage of our ACC lending library (from no tech to high tech) and who are hearing their children of all ages ask for what they need and want. When you have the

ability to ask and receive what you need, true communication and learning begins. Because of ACC, children understand cause and effect, make choices, and ultimately are motivated to learn for the first time. AAC, if done well, can be very powerful; if you would like to talk to a family whose child is benefitting from AAC, we will connect you. If you want to talk about setting up your child's Bay Area classroom for communication success, please make an appointment with SLP and AAC Specialist Kati Skulski at 510-381-9992, or you can e-mail her at kaskulski@gmail.com.

As stated in the beginning of my message, we cannot achieve our goals without the generosity of our community. We are fortunate to have a \$40,000 matching grant from our friends at the Quest Foundation. We do not receive these funds unless we raise the money. We do not actively ask our membership for dues, so I am asking you to help us kick-start 2013 by donating \$50, which, thanks to Quest, will turn into \$100. If everyone receiving this newsletter donated \$50, we would have \$115,000.

Thank you all for allowing the DSCBA to continue our mission. We are honored to serve the community, and we are constantly inspired by the strength of the families we serve. People with Down syndrome show us every day that we are only limited by the limitations we put on ourselves.

Thank You AT&T



Friends from AT&T who volunteered to help with carnival games for our Step Up walk. Above, left to right: Krista Veri, Dave Kappadahl, Susie Ferris-Inderkum.

Chelsea Brings Home the Gold

Lisa Werner

Looking back, who would have thought that Chelsea would make her way to London this year for the 1st World Gymnastics Championships sponsored by the Down Syndrome International Gymnastics Organization? Chelsea started gymnastics around the age of eight with Special Olympics. She had a hard time just standing on a balance beam. Her team met for about an hour once a week. This continued for a year or two, and then we decided to put her in a class at a local gymnastics gym. Her behavior and focus were a real problem; she was disruptive to the other students in the class.

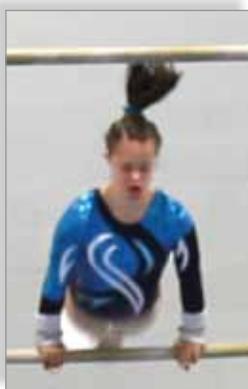
After discussing the problem with Katherine Sefton, we came up with a plan. Chelsea would be sent home as soon as she didn't follow the routine with the other students. The first few times she only lasted 5 or 10 minutes before we were on our way home. Within months, she was lasting the full 90 minutes and was making real progress.

Chelsea still participated in the Special Olympics program, but the season was so short that other parents, including us, thought it would be better to find a year-round coach. So my husband, Ray, picked up the phone book and started calling different gyms in the area.

That's when we met Dawn Pombo. She was tough with the girls. She didn't know what to expect as to how far the girls could go in this sport. One thing she has never done is to put limitations on Chelsea. She was willing to take her as far as she could go. Not too long after finding our new Special Olympics coach, Northern California dropped its Special Olympics gymnastics program.

Now what? Dawn thought we should try USA Gymnastics Special Olympics Championships. To compete in USA Gymnastics, the entry level is at level four, which is very tough. After about a year of training, Chelsea entered her first meet as a level four. She fell off the beam four times! Everyone clapped for her—probably because they felt so bad. Her other routines were a little better, but her scores were really low.

For about two years, Chelsea always took last place. As the other girls would receive their awards, Chelsea usually ended up in tears. Dawn and Chelsea's persistence finally paid off. Chelsea qualified to move up to level five! This involved learning much more advanced skills. Once again Chelsea's scores



*From left, Chelsea flies!
Chelsea shows no fear
World Gymnastics Champion*

were at the bottom. Chelsea was now training 12 hours a week. As the skills got harder, Dawn would figure out different techniques. Typical techniques were not always successful for Chelsea. Skills needed to be broken down into smaller increments and repeated over and over again.

A little over two years ago, we heard that Special Olympics was going to have its first USA national games for gymnastics competition. We entered Chelsea in the Special Olympics National Gymnastics Championships and traveled with her to Atlanta, GA. All Chelsea's hard work over the years paid off: Chelsea took first place! This past May, Chelsea successfully defended her title. While in Atlanta, we were informed about an upcoming World Championship gymnastics meet to be held in London in September. It was sponsored by the Down Syndrome International Gymnastics Organization. Chelsea started her fundraising, and Dawn started perfecting Chelsea's routines.

Then we were off to London! We went straight from the airport to the gym. In the weeks leading up to the competition, we were really confident that Chelsea would do well. Once we got to the gym though, Chelsea really struggled. She fell every time she attempted her bar routine. She couldn't make it through her balance beam routine without falling. The vault was the hardest adjustment of all. It was set in a position so high that none of the gymnasts could make it over. We decided to leave before all of Chelsea's confidence was gone. We went back the next day, and it was a little better. Chelsea's signature event, the uneven bars, was still a big problem. The officials were very strict about how much practice time was allowed so went back to the hotel very

apprehensive about how the competition was going to go the following day.

The opening ceremony was quite amazing! All the gymnasts from 12 different countries, including Norway, South Africa, Canada, and Brazil, marched in. They presented both the Olympic torch from the 2012 Olympic Games and the torch from the first time London hosted the Olympics. They also had the mascots from the 2012 Olympics. Now it was time for the competition to begin.

The Special Olympics rules state that before each gymnast competes the gymnast gets 30 seconds to practice. Chelsea's first event was her floor routine. She did great! Next came the balance beam: she managed to stay on and finished with a pretty good score. And the vault went better than expected! Her final event was the bar routine. She fell twice during her 30-second practice. Chelsea saluted the judges and started—a perfect bar routine! What a great way to end her competition.

At the awards ceremony, Chelsea was awarded the gold medal and declared the World Champion. They raised the United States flag and played the United States national anthem. It was so nice to see all the years of hard work result in such a rewarding experience! It was also very rewarding to have so many other gymnasts and coaches comment on how they were going to go back and work on things they had seen Chelsea do.

Next year the World Championships will be in Portugal. Several coaches from different countries approached Chelsea's coach, Dawn, and wanted to invite Chelsea to participate in their country's national competitions in 2013. It looks like we're back to fundraising again!

Top 10 Things I Have Learned while Navigating My Son through School

Teresa J. Unnerstall

High school graduation is a mere seven months away for my son Nick who has Down syndrome and autism. What a ride we have been on with the school system. Nick has attended school in Houston, the East Bay area of San Francisco, and the western suburbs of Chicago. The experiences have been unique in all three regions. By the way, not all states are created equal. Here is what I have figured out along the way.

1. Determine a method to communicate with the staff (e.g., communication notebook, e-mail, daily reports).
2. Meet with the support teacher to discuss goals for the following year. Request all goals and reports from each department for review before the Individual Education Plan (IEP) meeting.
3. Get everything down in writing in the IEP (from a 1:1 Aid to the chewy sensory toy and nubby cushion).
4. Know that you are not a bad parent because your child won't keep gloves on or has a meltdown in school.
5. Realize that sometimes the parent has to be the one to rattle the cage.
6. Get help when you need it (support groups, workshops, trainings, respite care, etc.).
7. Know your rights; a great website is www.wrightslaw.com.
8. Don't settle for just any solution if a problem doesn't get better. There is always a better way.
9. Understand that sometimes you have to let go of your own dreams for your child so they can move down a different path.
10. Trust that the parents are the biggest advocates for their child with special needs.

The parent is a key piece to the team. You know your child better than anyone. It is essential to open the lines of communication from the beginning and maintain them all through the school year (there will be no surprises that way). On occasion, when I felt like provisions were not being met for my son, I have sought outside support. When Nick was in first grade in California, the request for a communication system met deaf ears. I brought in Martha Hogan from the Down Syndrome Connection of the Bay Area. Her calm, steady demeanor and matter-of-fact approach made the whole team sit up straight and listen. We walked out of that meeting with the assurance that my son would get a picture exchange system in place. I left feeling more confident of how to advocate for my son.

I also learned to quit beating myself up because Nick had meltdowns. (Now I know that Nick felt powerless because he couldn't communicate his needs, and it was not my bad parenting.) Once the autism diagnosis was given, I realized I was not armed to fight the big fight. The best thing I did was to seek more training, support groups, and aid for respite care. By doing so, I realized there were other avenues to explore. I quit settling for the school staff solutions (that weren't always tackling the problem) and started thinking outside the box.



Nick's first day at first grade in Livermore, CA



Nick, the high schooler

A support teacher once told me this: "Sometimes our hands are tied due to budget constraints. But you, as the parent, can rattle the cage; they will listen and loosen the purse strings."

As parents, we all have aspirations for our child. I found that just because I have a dream for my son doesn't mean he can fulfill it. Sometimes you have to let go of your dream. You have to face the fork in the road. For Nick it was making the shift from academic course work to a functional curriculum. This enabled him to focus on what he was meant to do. Finally the most important thing I know to be true is this: Believe in yourself as a parent. You are your child's best advocate!

Read more by Teresa Unnerstall at her blog: www.nickspecialneeds.wordpress.com.

The Thomas J. Long Foundation Delivers \$15,000 in Support of DSCBA Programs



Check presentation and tour of the DSCBA facility (Left to Right) Sidne Long, Thomas J. Long Foundation Board President, Nancy LaBelle, DSCBA Executive Director and Robert Coakley Executive Director Thomas J. Long Foundation.



Sam Small is delighted when his mama tells him about all the neat things going on at the DSCBA!



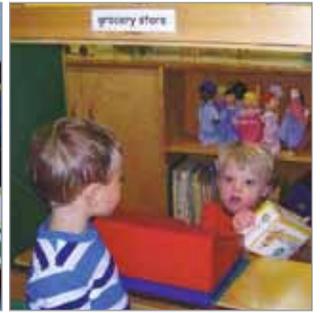
Cole Kelley enjoys Angry Birds on the iPad at the DSCBA office



Karina, right, and friend Tatiana celebrate Karina's 18th birthday. Happy Birthday!

Inclusion Works with a Great Team

Kathy Miles, Noah's Ark Preschool Teacher



Will Drucker attends our 13 member class for 3-year-olds at Noah's Ark Preschool at St. Timothy's Episcopal Church in Danville on Tuesdays and Thursdays from 9:00–11:30 a.m. Will comes into the classroom with a smile and enthusiasm. He participates in free play time, small group time, planned activities, and outside time. Will enjoys being with his peers, and his peers enjoy being with Will.

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WWW.FACEBOOK.COM/DSCBA



ALMOST 600 FANS SO FAR

WHY DON'T YOU
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GET UPDATES FROM THE CONNECTION AND LEARN ABOUT EVENTS, FANS CAN POST TEXT, PHOTOS AND VIDEO TO DSCBA'S PAGE.

Habitot Children's Museum

**DSCBA FAMILIES:
FREE**

ADMISSION PASS AVAILABLE



Otto celebrated his 1st birthday at Habitot this year on DSCBA family day.

The DSCBA has a family pass for the Habitot Children's Museum in Berkeley. This pass provides a free day of admission for two parents and all the children in the household. We have held two successful DSCBA family days for children ages seven and under, recently. This is a great place for kids to play and explore.

For more information about Habitot Children's Museum visit www.habitot.org.

If your family would like to go to the museum for the day, contact the DSCBA at 925-362-8660 and you will be given a pass to take with you.



Troy's in First Grade Now

Shelli Rhodes

Full inclusion at school is working wonderfully for Troy. Troy wants to do things just like the kids in "regular education" because he wants to be like them. He tries very hard to keep up, and when he needs it, the kids help him.



We were worried about a new aide before

Troy waits for the bus to go to full inclusion first grade on the first day. Very exciting!

school started, but she is awesome. She seems to know just how much intervention he needs. He asks her to move away and let him "do it myself." He has lunch with his class and does not want her to follow him so that he can be independent.

He is doing so well. His reading is just soaring—he has had a deep love of words since he was small. He reads above his first grade level and takes comprehension tests on the computer. He is starting to use an iPad with TouchChat more than before. He has a specialist who works with him in his classroom setting each week. He has some very busy days with transitions, but he seems to love all the activity: going to speech, OT, computers, library, APE, and science.

Since school started, only two days had any issue at all. Interestingly, they were both when Dusty went out of town on business, which supports the notion that many of our kids need normalcy and that their behavior can be affected when things are not "normal."

His aide, his teacher, and his full inclusion specialist all came to the educators' class and want to know as much as they can about children with Down syndrome. We are asking ourselves, "Is this for real?"

Congratulations to the Hawley family on the birth of their third son, Alec. Mom says, "Big brothers Liam and Carter are showering him with hugs and kisses."



The Steppin' Up class enjoys glass paint as parents and grandparents watch a masterpiece come to life.



Times Square

Gloria Delrio-Casadont

"Tatiana y Patrick, Tatiana y Patrick." This is what my mom, sister, nieces, and I yelled when we first saw the photo of them on the Sony TV in Times Square, New York City. The second time the photo appeared we were ready with the cameras; we wanted to get the best shot possible. We wanted a photo to keep for a lifetime, to always remind us that they had made it big—all the way to the Big Apple!

They've made it big because they have proven the doctors wrong. They have shown us their unlimited potential; they are proof of angels on earth; they are the reason that I know love can be totally unconditional; and they are who they are: two young adults born with that extra chromosome, which made it possible for them to be in the big screen in Time Square—unbelievable!

Did I cry? Sure I did, but this time, the tears were of joy and a feeling of happiness that is difficult to describe. Thank you, Kathy, for sending the photo that was chosen (from many) to be shown in New York for the 2012 Buddy Walk.



A photo of Tatiana and Patrick shown in Times Square, NY, in honor of this year's 18th Annual New York City Buddy Walk.



Damien Visits His Dad

In October, Damien Carlon and his mother, Cathy, flew to Camp Lejeune in North Carolina to surprise his father, Tom. Tom was in North Carolina for a short leave after working with the marines in Afghanistan for the past year.

Bella's Modeling Debut for the Everybody Plays Campaign

Melissa Lucia

Last year, Infantino, a San Diego-based toy company, and The Step2 Company introduced their Everybody Plays campaign, celebrating the unique faces, smiles, and styles of babies everywhere. They collaborated with super-awesome photographer and blogger Kelle Hampton, to capture some fresh faces for their packaging and website using real Infantino parents and kiddos. Kelle, by the way, has a vibrant, beautiful two-year-old girl named Nella with Down syndrome, who was happy to model for her mother. Bella was selected to be one of the models; so on October 16, Bella and Mommy flew to San Diego and back, all in one day, so that Bella could take part in this amazing campaign! It was a long day, but so worth the effort. Bella was a perfect model; we are hoping to see her in the 2013 toy catalog! Regardless, it was worth the trip just to meet Kelle Hampton, whose blog has brought me so much encouragement and joy over the past two years. If you have not read her blog, do yourself a favor and start following it! You can find it at <http://www.kellehampton.com/>. And next time you're looking for a toy or gift, consider Infantino and Step2. Not only do they make great products, but they are excited to celebrate kids of all abilities—and I think that is pretty awesome!



Bella struts her stuff, Hollywood style



Left Kelle Hampton captures the fun. Right Melissa, Kelle, and Bella

Adam Ferguson and Juliana Portoni Enjoy the Homecoming Dance

Nancy Ferguson

When Adam's teacher called to say Adam wanted to go to the Dougherty High School's homecoming dance, it was not breaking news. Adam had been talking about the dance for weeks; wearing a suit and tie had been the only prerequisite. What his teacher told me next was news. Adam wanted to ask his friend Juliana to the dance. So, with flowers in hand, he invited her. When he came home, I asked how it went. "She happy-cried and said yes" was his reply.



Above, Adam and Juliana, ready for the dance
At left, Adam asking Juliana to the homecoming dance

Adam and Juliana had a great time at the homecoming dance on October 13, 2012.



Patrick's Day as a Padre



Kathy Harkins

No other Serra Padre has worn #78 as Patrick does! Patrick's Uncle Perry coaches JV football at Serra High School. Patrick was invited to be a Padre for the day. He spent the game on the sidelines; he was in the team huddle; he ran with the team to the locker room at half time and was introduced to the homecoming crowd. He also received a football and a hat and had lunch with the coaches. What an amazing day! *Thanks, Uncle P!*

Thank You Chevron!



Our dear friend Marian Cathedral-King, *left*, from Chevron and her family, Jimmy King and Kathy Klimacki, volunteer to make gingerbread houses for the holiday party.



Thank You, Brownie Troop #30677

Third-grade Brownie Troop #30677 from Green Valley Elementary School in Danville surprised the staff at the DSCBA with a generous donation derived from their hard work at cookie sales this year. The troop asked great questions about the DSCBA and Down syndrome. Everyone enjoyed a tour of the facility and had fun playing with musical instruments. This gift was doubled to \$700 thanks to the Quest Foundation matching grant!

Halloween Fun Caught on Film



Inclusion and Acceptance at Its Best

Jennifer Cooper



Here is Eli Cooper at his regular volunteer gig at the local elementary school (which is also Eli's alma mater). He volunteers every Monday morning during reading time. Students enjoy reading to Eli, and he is able to help them if they get stuck on a word. They also love the stickers he gives after they finish a book! It's a wonderful, symbiotic relationship: he helps them with their reading acquisition, and they help him gain confidence interacting with children and initiating requests. We're thankful for open-minded and supportive teachers!

Rocking the Runway for Charity

By Mary Erickson



Marissa showing glam on the runway

Marissa Erickson had a dream come true when she was asked to be a model in the annual Community Assistance for the Retarded and Handicapped (CARH) fashion show. CARH operates several thrift stores in the Bay Area; all the fashions for the 1940s theme show came from the thrift store. Marissa walked the red carpet for a sold-out crowd. We are so proud of her!

Community Outreach



Board President Terese Ghilarducci spreading awareness at the 2012 Danville Chamber of Commerce Business Showcase

Team Drucker

Katy Drucker

Every year our family has the opportunity to gather our friends and family to promote awareness and acceptance and to celebrate Will at the Step Up for Down Syndrome walk. Will was born in 2009, and we walked shortly thereafter with a small team of less than 20 people. Three years later, our team has grown to more than 100 people, and our family couldn't feel more blessed. Team Drucker is an amazing group of people who support us year round with prayers, carpooling, baby-sitting, meals, and friendship.

Most of Team Drucker is local, but people fly here just to walk with us. My best friend from childhood flies out from Arizona every year with her children to walk; my parents come from southern California; and several people come from San Francisco and the Peninsula. This year, my oldest sister and nephews from Arizona joined us, too.

As if that weren't special enough, our pastor asked the congregation to walk with us. He didn't hold the Sunday service so that people were free to walk. Furthermore, Will started preschool this year at Noah's Ark, where his brothers and sister attended, and one of his teachers, Kathy Miles, came to walk with us. Kathy is also the new reading specialist at DSCBA. Several people weren't able to walk, but donated generously via our fundraising page.

Team Drucker

If you were at the walk, you probably saw some people carrying Team Drucker signs or name tags. Several of the kids that walk



Will, holding a Team Drucker sign

with us made the signs at our house prior to the walk. The kids are invited to come hear a story about Down syndrome and then to make posters. This year I read *Taking Down Syndrome to School* to the kids to try and help them understand what Down syndrome is, which hopefully makes the walk more meaningful to them. The children have an opportunity to ask questions afterward, and then they make posters and play. Now that Will is three, it is fun to watch him play with the kids and help with the posters, even though he's clueless that they are for him.

When our friends and family unite with us at Little Hills Ranch, it is hard to describe my feelings. I see a huge group of smiling people with Team Drucker name tags, excited to walk with my family and me. It is overwhelming; it is humbling; it is a gift, just like Will. Thank you so much, Team Drucker, for all of your love and support!



Spring 2013 Step Class Schedule

DANVILLE LOCATION CLASSES

MUSIC THERAPY

Therapist: Nicole Patton, MA, MT-BC
1st Saturday of every month
Jan. 5, Feb. 2, Mar. 2, Apr. 6, May 4, June 1
Ages 0–4 years
10:00–11:30 a.m.

BABY STEPS

Facilitator: Martha Hogan
3rd Wednesday of every month
Jan. 16, Feb. 20, Mar. 20, Apr. 17,
May 15, June 19
Ages 0–3 years
10:30 a.m.–12:00 p.m.

SMALL STEPS

Teacher: Laura Briggs
Ages 5–8 years
Monday: 3:30–5:00 p.m.
Session 1: Jan. 7, 14, 28, Feb. 4, 11
Session 2: Feb. 25, Mar. 4, 11, 18, 25
Session 3: Apr. 8, 15, 22, 29, May 6, 13

STEPPIN' UP

Teacher: Laura Briggs
Ages 8–13 years
Wednesday: 3:30–5:00 p.m.
Session 1: Jan. 9, 16, 23, 30, Feb. 6, 13
Session 2: Feb. 27, Mar. 6, 13, 20, 27
Session 3: Apr. 10, 17, 24, May 1, 8, 15

NEXT STEP

Teacher: Marianne Iversen
Ages 13–19 years
Tuesday: 4:00–5:30 p.m.
Session 1: Jan. 8, 15, 22, 29, Feb. 5, 12
Session 2: Feb. 26, Mar. 5, 12, 19, 26
Session 3: Apr. 9, 16, 23, 30, May 7, 14

STEP IN

Teachers: Virginia Bonham and Tamara Reed
Ages 19 years and older
Thursday: 4:00–5:30 p.m.
Session 1: Jan. 10, 17, 24, 31, Feb. 7, 14
Session 2: Feb. 28, Mar. 7, 14, 21, 28
Session 3: Apr. 11, 18, 25, May 2, 9, 16

ADULT CLASSES THROUGHOUT THE BAY AREA

SF STEP

Teachers: Harold Burns and
Christina Lewis
Location: John O'Connell
High School, School of Technology,
2355 Folsom St. Room 111,
San Francisco
Tuesday: 4:00–5:30 p.m.
Session 1: Jan 8, 15 22, 29,
Feb. 5, 12
Session 2: Feb. 26,
Mar. 5, 12, 19, 26
Session 3: Apr. 9, 16, 23, 30,
May 7, 14

STEP OUT

Teachers: Harold Burns and
Virginia Bonham
Location: Interplay (Body
Wisdom Inc.)
2273 Telegraph Rd., **Oakland**
Wednesday: 3:45–5:15 p.m.
Session 1: Jan. 9, 16, 23, 30,
Feb. 6, 13
Session 2: Feb. 27,
Mar. 6, 13, 20, 27
Session 3: Apr. 10, 17, 24,
May 1, 8, 15

BENICIA STEP

Teacher: Tamara Reed
Location: PACE Benicia
425-E Military East, **Benicia**
Wednesday: 4:00–5:30 p.m.
Session 1: Jan. 9, 16, 23, 30,
Feb. 6, 13
Session 2: Feb. 27,
Mar. 6, 13, 20, 27
Session 3: Apr. 10, 17, 24,
May 1, 8, 15

Support Groups • January – June 2013

SUPPORT GROUP FOR PARENTS WITH CHILDREN AGES 0–3

Facilitator: Martha Hogan, Location - DSCBA, Danville
4th Tuesday, *every other month* • 7:00–9:00 p.m.
Jan. 22, Mar. 26, May 28, July 23

SUPPORT GROUP FOR PARENTS WITH SCHOOL AGED CHILDREN

Facilitator: Martha Hogan, Location - DSCBA, Danville
3rd Wednesday of every month • 7:15–9:00 p.m.
Jan. 16, Feb. 20, Mar. 20, Apr. 17, May 15, June 19

SUPPORT GROUP FOR PARENTS WITH TEEN AND ADULT CHILDREN

(For parents with children of all ages, the primary focus is on educational issues.)

Facilitators: Marianne Iversen & Tamara Reed,
Location – DSCBA, Danville
3rd Thursday, *every other month* • 7:00–9:00 p.m.
Jan. 17, Mar. 21, May 16, July 18

SUPPORT GROUP FOR GRANDPARENTS

Facilitator: Martha Hogan, Location – DSCBA,
Danville, 4th Wednesday of every month
10:00–11:30 a.m.
Jan. 23, Feb. 27, Mar. 27, Apr. 24, May 22, June 26

SUPPORT GROUP FOR FATHERS*

Facilitator: Dr. Rick LaBelle

SUPPORT GROUP FOR SIBLINGS*

Facilitator: Terese Ghilarducci

*If you are interested in learning more about either of these groups please call the Connection at 925-362-8660

Please RSVP prior to the meetings
925-362-8660 or dscba@dsconnection.org

SAVE THE DATE

DSCBA Bowling for Dollars



BRING YOUR FAMILY AND FRIENDS!!

SUPPORT PROGRAMS AT THE DOWN SYNDROME CONNECTION

Sunday, April 7, 2013

EARL ANTHONY'S DUBLIN BOWL ☆ 12:30 P.M.– 3:00 P.M.

\$7 per person
INCLUDES 2 GAMES AND SHOE RENTAL
Bumper Lanes Available

\$20 per ticket
QUEST RAFFLE CHALLENGE
An iPad mini and \$100 iTunesgift card will be raffled

Refreshments are available for purchase

Every dollar collected from raffle will be
matched by our friends at the



Small Steps

Laura Briggs

We are off to a roaring good start! We began this session with a terrific book, *Polar Bear, Polar Bear, What Do You Hear?* by Bill Martin Jr.

We made polar bear masks, hanging snakes, peacocks, and great elephant puppets. We put our elephants through some grueling relay races with peanuts and then cracked open the peanuts and ate them. Such fun!

Clockwise from right:
Hailey feeding her elephant.

Ainsley and Trevor sharing peanuts.

Elephants interpreted by Alex Walters, Hailey Wollesen, Ainsley Dodge, and Trevor Curran.

A peanut race between Hailey and Ainsley



Step Out

Harold Burns

Step Out in Oakland is continuing to dance and build friendships within our group, practicing respect for each student's unique communication style. We have also started exploring the possibilities of non-verbal communication via pantomime and charades to great delight and laughter. Further, we have just begun playing with synchronized movement, which requires students to actively focus on a partner's or leader's movement combination. This requires tremendous focus, but we are cherishing our slow and steady progress.

Step In Celebrates Jay's 60th Birthday

Virginia Bonham

Jay Purchio's birthday celebration was a great hit with his new Step In friends. Jay turned 60 years old on October 11. How lucky we were that he chose to celebrate this big milestone birthday with us. In classic Step In style we partied with pizza, cake, and dancing. Thank you, Jay, for coming to Step In and sharing your birthday with us!



Clockwise from top left: Jay and Virginia admiring the birthday cake, Jay and K. Leigh Alfrey, Step In celebrating and Jay's birthday cake



DOUBLE YOUR DONATION FOR DOWN SYNDROME

For a limited time, the Quest Foundation will match your gift to the DSCBA dollar for dollar up to \$40,000!

Avery, DSCBA Member

DSCBA needs your help to continue our support of families like these:

\$50 becomes \$100 • If everyone reading this message sends in \$50 we will start 2013 with over \$100K

"When our son was born, the Connection quickly became a key part of our lives. It was, and still is, a sweet and sorely needed combination of a living library of information, genuine compassion, complete support and a warm Grandma's hug—all rolled into one."

"Someone I love very much has benefited greatly from the services provided by the Connection."

"I've been involved for the past year with the Down Syndrome Connection—and they've been awesome! I've met lots of great friends and have learned a ton from them. They work so hard, every day, to help make sure that I, and other kids and adults with Down syndrome, have all of the same opportunities as everyone else to become the best that we can be."

"Our son will be able to thrive and grow in ways he probably would not have had the chance to without the DSCBA."

"We are so fortunate to have such a valuable resource in the Bay Area. We love this organization and appreciate what they give to us, to other families we have met, and what they give back to the community."

"Their education advocacy has been especially helpful as we have navigated the school system in preparation for our son's kindergarten year—which is off to a great start!"

"I've been attending my Step class for the past 7-1/2 years at the Down Syndrome Connection and it has been so much fun and really helpful in helping me with social skills and meeting some great people."

"We've seen firsthand the impact that the Down Syndrome Connection has made in the life of our cousin and his family. It is an amazing organization run by dedicated people who help those born with Down syndrome live lives of grace and dignity."

Use the envelope included in this newsletter to make a special gift to the DSCBA, which will be **matched dollar for dollar** by the Quest Foundation.

Or go to our website: www.dsconnection.org and click on the **Donate Now** button on the home page.



Down Syndrome Connection
of the Bay Area

Thank you for your support!



DSCBA Members Step Up for Down Syndrome!

Nancy LaBelle

With over 1,000 people in attendance, including 100 dedicated volunteers, we had another great walk on October 7 at Little Hills Ranch. Thank you to our amazing DSCBA staff and board, the Little Hills staff, and the many volunteers for the countless hours and hard work that make the event a very special day each year.

This year, walkers included many new families, as well as families whose teams continue to grow in support and love year after year. For the first time, we had a generous corporate platinum sponsor, Macy's, who attended with a great group and fun prizes. Thank you to Mechanics Bank and Umpqua Bank for sponsoring our T-shirts this year. Karaoke was a big hit, and the carnival games, rock wall climbing, fishing, and bouncy houses were all very busy.

The proceeds from this event account for almost 30 percent of our annual budget, which allow us to continue our vital programs and services. Each year we challenge our membership to send out a fundraising webpage in support of someone you love. In 2011, you met our \$100,000 challenge by bringing in \$125,000 in online donations alone; this year, you raised an amazing \$139,000 online. With Macy's sponsorship and many generous offline donations, together we raised \$170,000, surpassing our 2012 goal of \$150,000. Congratulations and thank you!

This year, 98 families sent out a webpage and raised amounts from \$50 all the way up to \$16,000. As you can see, your collective fundraising makes a difference. Congratulations to our top three fundraising families: the Zolnier and VandenBerghe family, in first place, raised over \$16,000, and the combined amount from the Dodge and Garcia families was over \$25,000. In fact, the top 10 fundraising families raised \$70,000 just by e-mailing a webpage out. If you haven't sent a webpage, I ask you to please consider it in 2013. We have the potential of raising over a quarter million dollars each year if everyone e-mailed their friends and family.

We cannot be more grateful to the over 2,000 donors who gave so generously this year and who continue to support our organization annually. Our doors do not stay open without our generous members, their extended families and friends, and a giving community.

I hope you had a great time. We look forward to next year, during National Down Syndrome awareness month, when we will proudly walk again to promote positive awareness, acceptance, and inclusion for all. Save the date, October 6, 2013. See you there!



Step Up Walk photos: Lisa Upton of Lisa Upton Photography





SAVE THE DATE
May 4, 2013

Annual Gala for Giving

Benefitting the Down
 Syndrome Connection
 of the Bay Area

DIABLO COUNTRY CLUB

Appetizers, cocktails, dinner, live
 and silent auctions, raffles,
 dancing, and more.
 Get dressed up and join
 in on the fun!

**WATCH FOR TICKETS
 ON SALE IN MARCH**

NOTE:

We need your help!
 If you have contacts for auction
 items such as rental homes,
 vacations, limousines, wine
 country items, jewelry, and
 other local services, please
 let us know ASAP.

Left to right: Tatiana, T. J., Patrick, Adam, and Grant



At right: Emma Tippet and Julianna Portoni



Above: Grant Riley, Patrick Harkins, Julianna Portoni, T. J. Crawford, Adam Ferguson (front)

Next Step

Marianne Iversen

Next Step has been having great fall fun. The class made ghosts from cheesecloth and starch (great sensory fun) and then sold them to earn money for a field trip. The class voted to spend the earnings on a trip to the local bowling alley.

For Halloween the class played a skeleton game that involved putting together skeleton body parts; this enabled great conversation about right and left limbs!

It is never a dull moment in Next Step as the friendships continue to grow and strengthen.

Benicia Step

Tamara Reed

Benicia Step enjoyed making signs in preparation for the Step Up for Down Syndrome Walk. On the day of the walk, the Step members also had a wonderful time greeting the walkers as they entered the park.



Getting ready for the Step Up walk



Benicia Step greets the walkers

SF Step

Harold Burns

This session, SF Step has returned for a second year to our Día de los Muertos altar project to provide students an opportunity to contextualize the grief that many continue to feel for relatives and friends (and pets) long after they have passed. Each student created a multi-layered *altar* that represented some of the loving memories they had of their time with the person who had passed. This project has been a great creative emotional outlet for the students as well as a perfect opportunity to practice empathy, understanding, and mutual support for one another.

At left: Nina Byers-Straus Below from left to right: Emma Darby, Nina Krietzman, Emma Yungert, and Christopher Vidales



Skin Disorders in Down Syndrome

Tracy L. Trotter, MD, FAAP



Dr. Trotter

Patients with Down syndrome (DS) are affected by chronic skin conditions more often than the general population. Our skin is the largest organ in the human body and serves a number of important functions. It provides a critical layer of protection, a host of neurological functions (the sensation of touch, pain, heat, and cold), and is our most important heat regulator. This article will discuss

the skin conditions that are more common with people having DS than with the general population. The general rule is that most of these problems are minimal in the first years of life and become more of an issue in late childhood or adolescence.

XEROSIS (DRY SKIN): The skin tends to become abnormally dry and rough during the early school years (5–10 years), and by 15 years of age the majority (70–80 percent) of children will have generalized dryness requiring therapy. This is best managed with nondrying soaps (Aveeno, Cetaphil, Dove, Neutrogena, Oil of Olay) and moisturizers.

HYPERKERATOSIS (THICKENED SKIN): Usually noted on the palms and soles, this can also appear as rough bumps on the upper arms and thighs. It is not typically treated, but topical lotions that contain urea and/or salicylic acid are of some benefit. Hyperkeratosis is found in 75 percent of patients by 18 years of age.

CHEILITIS (CRACKING AT CORNERS OF THE MOUTH): This presents as fissures and red, scaly skin at the corners of the mouth and lips. Cheilitis may be complicated by bacterial or yeast infections. It is treated with mild steroid creams, along with active treatment of infections when they occur. Frequency and severity of this condition increases with age.

ATOPIC DERMATITIS/ECZEMA: This red, scaly, itchy condition appears most often on the cheeks, behind the ears (may cause cracking), and in the creases (neck, elbow, knee). More than 50 percent of patients have this problem. It can be seen at any age, although it is more common among infants and toddlers. Treatment with topical steroids, moisturizers, and oral antihistamines is usually needed on a continual basis. Occasionally, diet will impact atopic dermatitis, with milk and wheat being the most common issues.

“As you can see, the skin of patients with Down syndrome is high maintenance.”

SEBORRHOEIC DERMATITIS: This is actually another of the atopic dermatitis group, but presents as greasy and scaly lesions in the scalp and eyebrows. Treatment is with dandruff shampoos and occasionally topical medications obtained by prescription.

TONGUE LESIONS: Although not harmful or requiring treatment, a fissured tongue (grooves in the tongue of varying depths) occurs in 80 percent of children with DS, and geographic tongue (map-like appearance due to irregular patches) is seen in 10 percent of patients by 18 years of age.

SYRINGOMAS (BENIGN SKIN TUMORS): These harmless tumors arise from the sweat ducts and appear as multiple raised nodules usually around the eyes, neck, and chest. They are seen twice as often in females. Although they do not require treatment, they can be removed surgically or with lasers.

VITILIGO (LOSS OF PIGMENTATION): These patches of skin without pigment can occur on any part of the body and at any age. No therapy is indicated; it is harmless.

ALOPECIA AREATA (PATCHY HAIR LOSS): This patchy hair loss occurs five times more often in DS patients and is unpredictable. It

can occur one time or repeatedly. It typically regrows (but not always) and varies in size from a dime to a silver dollar. Very rarely it can involve the entire scalp (alopecia totalis). Treatments include topical medications such as minoxidil and steroid injections in the scalp. Even without treatment, the majority of patients will have hair regrowth.

This condition is felt to be an autoimmune disorder, and because autoimmune diseases (hypothyroidism, celiac disease, diabetes) are more common in patients with DS, these conditions should be investigated when alopecia occurs.

ACANTHOSIS NIGRICANS (INCREASE IN PIGMENTATION): This increased pigmentation most often occurs on the nape of the neck, lower arms and hands, and the groin. It has a thick, velvety feel and is frequently mistaken for dirt that won't wash off. This is not a harmful condition, and there is no effective treatment.

ELASTOSIS PERFORANS SERPIGINOSA (RED, RAISED LESIONS): This is a disorder of the elastic tissue of the skin and occurs mostly in males (80 percent) between the ages of 10–30 years. It appears as deep red, raised lesions usually in a line or a circular pattern. Although usually of the back and sides of the

Skin Disorders, continued on page 21

Skin Disorders, continued from page 20

neck, it can be anywhere. The lesions usually disappear, but they may last 10 years or more before that happens. Some dermatologists treat this with liquid nitrogen (with mixed results).

Skin Infections

BACTERIAL INFECTIONS: A variety of bacterial skin infections affect patients with DS. This is due to the decrease in both the protective quality of the skin and the less than optimal immune response to infection. The most common (and annoying) of these is folliculitis. Folliculitis is the infection of hair follicles of the skin. It starts as red bumps and progresses to pustules and potentially boils or abscesses. It usually occurs in the groin or thighs and increases dramatically during adolescence. Treatment includes antibacterial soaps, topical antibiotics, and oral antibiotics when necessary. The majority of these infections is due to the staphylococcus bacteria. Unfortunately, this is often a continual battle for adolescents and young adults.

FUNGAL INFECTIONS: The typical fungal infections of the skin, athlete's foot and jock itch, occur in greater frequency in DS patients, and respond well to topical antifungal creams. Fungal infections of the nails (onychomycosis) are also prevalent and often require oral antifungal therapy. Recently, there is some use of lasers for the nail infections, but expense and lack of insurance coverage have thus far limited its use.

PARASITIC INFECTIONS: Scabies, an infection of the skin with a microscopic mite, is a common problem in adolescents and adults with DS. It is contagious and transmitted by skin-to-skin contact. This rash is extremely itchy (especially at night) and appears as rows of red dots. It is most often seen in the webs between fingers, the waist line, and the buttocks. It is effectively treated with a topical permethrin cream.

As you can see, the skin of patients with Down syndrome is high maintenance. Although not typically of significant harm, these can all be annoying conditions that impact the quality of life and require continual attention.

Counting to 10

Terri Mauro

Terri Mauro has two children with special needs: a 22-year-old with language-based learning disabilities and a 19-year-old with Fetal Alcohol Spectrum Disorder, both adopted from Russia in 1994. She estimates that she has been to 32 IEP meetings over the course of 17 years of advocating for her kids and celebrated her final one in the winter of 2012.

When it comes to getting kids to do what they're told, three seems to be the magic number. The success of books like *1-2-3 Magic*—and maybe the success of our own parents in telling us we had a three-count to hop to—makes us assume that if our kids don't get moving in a similar time frame, they're being disobedient. But for children with special needs, three may be a very unrealistic number. Think about what you're asking your child to do when you give an order and start counting. He or she must (1) figure out what you want done; (2) figure out how to do it; and (3) do it. Can your child negotiate those three steps in three seconds? Don't be too quick to say yes. Consider these possible problems:

Auditory processing. If your child has trouble processing language, it may take more than a count of three for him or her to figure out what you want done, much less how to do it.

Motor planning. For some children, figuring out how to physically do something—even something as obvious as stopping what they're already doing—can be a multi-step process. Planning and sequencing the activity may be a bigger job than a count of three will allow.

Stress management. Some people find deadlines energizing, but others

can become paralyzed by them. Anxiety caused by deadline pressure can take over your child and cause him or her to be unable to focus on the task at hand.

Frustration tolerance. If your child feels unable to obey for any reason, it may seem easier to invite punishment than to do what's called for. A count of three gives your child very little time to work through other possibilities.

If any of these are problems for your child, you may find you will have more success if you extend that "count of 3" to a "count of 10." Counting to 10 gives your child adequate time to either process your request or ask for clarification; to transition from what he or she is doing to a different activity; and to deal with frustration without becoming overly stressed. You may find that your child sometimes needs less than 10, at which point you can provide praise and encouragement. And if 10 is reached and the behavior hasn't changed, you can still provide your consequence.

Giving your child more time to do what you ask may seem like a sign of parenting weakness, but if you have reason to believe that your child can't comply in short order, it's not only merciful but practical to extend the deadline. Your goal, after all, is to have your directions followed. In the end, it's far more efficient to spend seven extra seconds and get what you want than spend minutes and hours dealing with the consequences of disobedience. Patience, after all, is a virtue.

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Common Misconceptions about Augmentative Alternative Communication (AAC)

Ajit Narayanan, CEO of Invention Labs

1. My child can talk—if she uses an AAC aid, she will not feel motivated to develop natural speech.

This is the most dangerous myth of all. Withholding communication and trying to insist on natural speech prevents a child from experiencing a normal childhood, with new experiences, expressing curiosity, and making friends. Even for those children who do become verbal eventually, research has shown that using an AAC aid actually assists the process, instead of inhibiting it.

2. My child is too young to get started with AAC.

This is related to the “can talk” myth. Thirty years of AAC use have demonstrated very clearly that early intervention is key to managing disabilities effectively. The brain is very plastic before the age of 6—new neurons are created, and new connections are formed between different parts of the brain. Picture-based AAC aids work by bypassing the brain’s verbal center and instead using the visual center or language-planning center for developing language. The earlier the intervention, the greater the likelihood of success. I’ve

seen great successes in AAC intervention with kids as young as 2.

3. My child doesn’t have the cognitive ability to ever be able to read or write.

This is false in the vast majority of cases—no child is too intellectually impaired to read or write. And it is certainly the wrong attitude to not even try. Difficulties in literacy that stem from the complicated symbolism of language: alphabets, written words and spoken words have no relationship at all to the objects they refer to, and may be hard for a child to learn these abstractions. However, if we replace words with pictures, the symbolism is much easier, and many children can access reading materials and education, so long as it is in a format that they can easily access.

4. Investing in education and AAC is ultimately pointless: my child will never be able to join mainstream society.

We’ve come a long way in integrating people with visual and hearing impairment into mainstream society, and children with developmental disabilities can achieve integration even faster. The real question is: when opportunities in society do arise,

will your child be prepared? The only way is to invest in education and AAC now.

5. AAC aids aren’t good enough to replace natural speech—so my kid shouldn’t use it.

It’s true that language and speech are two of the most complex functions of the brain, and it will be a long time before we can perfectly replicate them in computers. But the pace of research and development in this space has never been faster, and with the iPad and other tablets becoming so common in intervention, the number of people working on the problems increases every day. It isn’t necessary for the technology to be perfect for it to be useful. The mistake is not to try—the biggest mistake is to withhold something useful, just because of a myth or a misconception.

This article was written by Ajit Narayanan, the inventor of Avaz. Avaz is an award-winning AAC app for children with speech disabilities, with a particular focus on autism. The original article can be found at <http://www.avazapp.com/2012/11/14/some-common-misconceptions-about-aac/>. Read more by Ajit Narayana at his blog www.avazapp.com.

Steppin’ Up

Laura Briggs

Costumes, popcorn, and Scooby Doo—what more do you need for a great Halloween movie day? Oh I know, “blood” punch with a severed hand in it!

We checked out four movies then voted for our favorite. After gluing our choices on a chart, we saw we had a tie! So we decided by a tiebreaker, and the winner was *Scooby Doo 2*. We had a great time laughing at Scooby and Shaggy and shivering at some of the scarier monsters.

Sometimes it’s even better than going to the movies because we can talk through the whole movie.

At right: Daniel Sodestrom, Shawn Swienton, Clio MacNair Rasler and Anthony Godinez

Below: Daniel, Clio, Shawn and Anthony



When Is It Appropriate to Tell Our Child He or She Has Down Syndrome?

Martha Hogan

It has been brought to my attention lately that some parents want to know when to tell their child about having been born with Down syndrome, and, in addition, when is it appropriate to tell the siblings? It is my feeling that you will know when the time is right. Every family is different. The important thing to hold on to is that your child is who he or she was meant to be, just like all of us. Each child is unique. And yes, Down syndrome can and does impact the child's life and the lives of others, but it does not necessarily mean that it is a negative impact. It certainly can be tricky, but with time and understanding, the spotlight will become less on Down syndrome and more on what your child brings to the family as a whole. Our children grow up with each other and learn to understand what might come easy and what might challenge all of

us. As your children grow, necessary therapies will become a natural course of events that take place during the week and in the school setting. It is also a time to meet new friends and families that you might never have had the opportunity to get to know. In other words, Down syndrome is an important part of who your child is and should not be thought of as something that will separate you from others.

In my experience, children with Down syndrome and their siblings will ask questions from time to time. Children with Down syndrome will know some things are hard for them and wonder why. I suggest that you answer their questions in the simplest and most honest way possible. It is not necessary to talk about the complexity of chromosomes, but it is essential to be positive in your explanations so that all



Martha and her son, Blair

family members see their brother or sister in a positive light. And as a result, the child with Down syndrome will also grow up having a positive sense of self, no matter what the challenges may be.

I hope this will help you to embrace the challenges that lay ahead of each one of us. It is a journey that will bring more blessings than you ever envisioned.

May 2013 be filled with joy and celebration.

Rachael's Teacher Rocks

Natalie Burbach

Rachael is in second grade, with the full inclusion program at Livermore's Sunset Elementary School.

A couple weeks into school, her inclusion specialist and I decided that Rachael should be given only one word and one math problem so that she could keep up with the flow of the class. When I told Rachael's teacher this, she looked very confused and said, "But Rachael can do more than that." That night I wrote Mrs. Anderson, Rachael's teacher, an e-mail and told her that I was sorry: I was going about this all wrong. She is the teacher; she is in charge, and I trust her—so I was going to back off. The next day Mrs. Anderson thanked me for the e-mail.

Two weeks later Rachael came home with her 10 spelling words! I thought, oh boy, these are a lot of words for Rachael to learn in a week, but OK, we'll try. I'm so proud to show you her spelling test, 80 percent! Go, Rachael! Go, Mrs. Anderson! She was so right—I would have *never* thought that Rachael could do this!

Mrs. Anderson recently attended the training for educators at the Down Syndrome Connection. The day after the training, Mrs. Anderson made some changes at school. She asked Rachael's aide *not* to unpack or pack up her backpack anymore; Rachael is capable, and we are just hindering her by not allowing her to do this herself. She also told



Good job, Rachael!

me that she would occasionally take pictures of Rachael while she is in school and text them to me. This picture is the first picture I received! I was so excited to get this on my phone in the middle of the day; it brought me to tears of joy.

Thank you, Down Syndrome Connection, for offering to be a support to our wonderful teachers, and thank you, Mrs. Anderson, for being the *best* teacher! What a blessing you both are to us.

Common Acronyms in Special Education

ABA:	Applied Behavior Analysis
APE:	Adapted Physical Education
ASL:	American Sign Language
BIP:	Behavior Intervention Plan
ESL:	English as a Second Language
ESY:	Extended School Year
FAPE:	Free Appropriate Public Education
FBA:	Functional Behavioral Assessment
IDEA:	Individuals with Disabilities Education Act
IEE:	Independent Educational Evaluation
IEP:	Individualized Education Plan
LRE:	Least Restrictive Environment
NCLB:	No Child Left Behind
PECS:	Picture Exchange Communication System
PLP:	Present Level of Performance
PWN:	Prior Written Notice
504:	Section 504 of the Rehabilitation Act and the Americans with Disabilities Act

Down Syndrome Educational Alliance Update

Jennifer Cooper



We at the DSCBA have been working hard this fall to educate more than 250 Bay Area educators in over 20 districts. We've hosted several Down Syndrome (DS) 101 trainings for special education teachers, psychologists, therapists, general education teachers, paraprofessionals, preschool teachers, and administrators. Our training focuses on the general physical and cognitive functions and profiles of students with Down syndrome. The key word there is *general*: as we all know that there is no one model, blueprint, or manner in which students with Down syndrome learn. We can, however, illustrate what research and experience have taught us about the strengths and challenges that many students with DS have with physical and medical complications, communication, behavior, memory, processing, and more.

That information is used as a platform for us to discuss strategies and methods for encouraging academic, communication, social, and emotional growth for students with DS in the classroom. We address strategies to reduce "learned helplessness" and the importance of doing so. We also address increasing ability awareness in the community and integrating peers as friends and support for students with DS. We attempt to touch on most of the main areas that affect students with DS, including AAC, dual diagnosis, medical complications, as well as general learning profiles. It is a lot of information, and we have had to compact it.

We have received only positive responses from educators thus far. It is evident, and truly remarkable, that they have had little to none of this information prior to our training. Several educators have come to more than one training (and it is the same material) just for another opportunity to take it all in. We intend to provide more intensive and topic specific

training in 2013, while still continuing to provide DS 101 to those who haven't had it yet. If you know folks who are working with your child with DS and have not yet benefited from this training opportunity, please feel free to refer them to us. We are also considering presenting the DS 101 class to parents, if enough are interested. We thought you might like to know what we are telling your students' teachers! Please let us know if this is something that would interest you. If you have stories or examples of things that are working well for your child in the classroom, we want to hear them! We want to share stories of success and

"...we all know that there is no one model, blueprint, or manner in which students with Down syndrome learn."

innovative ideas so that we can all learn from one another. We've already heard stories of how AAC is helping one child with her spelling tests, how peer support is being used to help one child transition from one activity to the next, and how several children are benefiting from the 10 second rule.

This is an evolving program, and we are learning so much as it does. We refine and reshape the content, platforms, and ideas as the program progresses. The one constant is that we are all striving to give students with Down syndrome the best chance at reaching their fullest potential—and they are achieving great things!

Here are some samples of comments from surveys taken by DS 101 class attendees:

"This training was extremely helpful in having a better understanding of individuals with Down syndrome and their

strengths, medical issues, special needs, helpful modifications, etc."

"Thank you for this program; it is so comforting knowing that we can work together and share with parents."

"I enjoyed the class and found it very informative. The info shared is great for sharing with school's staff."

"Thank you for a very informative seminar! You gave me some wonderful techniques to work with all of my students."

"I really enjoyed the presentation and felt that I have some good tools to take with me."

"I learned ways to help my student meet and interact with other students."

"Now I know that there are resources that are available to me."

"I learned that it is important to expect more from individuals with Down syndrome."

"Hearing about the 10 second rule hit me like a ton of bricks! So many times, I have asked a question and, after what seemed like forever with no response, moved on and then had an answer 10 seconds later. It really makes sense that they are processing the information; if you give them that extra time, the answer is there and wants to come out. It really opened my eyes. Great seminar!"

Educators' responses to what they learned from the DS 101 training:

- Make sure that the materials given are challenging.
- Allow the student processing time; wait 10 seconds before prompting.
- I learned strategies to make the student more successful.
- Inclusion is belonging.
- Give fewer cues.
- Medical issues associated with DS.

An important note: We are grateful that Nancy LaBelle had the drive and vision to implement this program. Thank you, Nancy!

SIBLING CORNER

Parents of children with Down syndrome often worry about how to meet the needs of the other children.

Tips for Parents

Treat the child who does not have a disability as a child, not just as another adult care person. Do not demand or expect a child to take on responsibilities for which he or she is unprepared.

- Remember that children have feelings too. Take time to ask them how they feel about having a sibling with a disability. Encourage them to express their feelings openly even if you don't like what you hear.
- Provide siblings with choices and include them in decision-making. Discuss family matters with your children, especially if it affects them personally. Ask for and consider their opinions and advice.
- Give them information about their brother's or sister's disability. Answer their questions and respond to their concerns in a simple but precise manner. Emphasize that no one is to blame for their brother's or sister's disability. Come to terms yourself with your child's disability.
- Encourage siblings to see their brother or sister as an individual with similarities and differences to themselves.
- Meet other families who have a son or daughter with Down syndrome, perhaps through a local support group.
- Spend regular time with your child—have a special time for him or her each day.
- Celebrate your child's achievements, even the small ones.

Quotes from Siblings

How has having a sibling with Down syndrome changed your life?

"I am much more caring to other people, but sometimes I have to look after her; she can be a pain."

"I felt that I never got my parents' full attention, and her needs had to come first. As I got older, I realized that this was how it had to be, but as a child it was hard to accept at times."

"I am more caring for others and understand other people's disabilities and will stick up for anyone who is getting bullied for whatever reason."

"It's opened my eyes to how loving people can be—and how horrible. Tom is the most caring, up-front person I've ever met. He's totally non judgmental and doesn't know the meaning of the word embarrassing. I wish I could be more like him!"

"It has made me consider a career in health care or education. It also means that things I may have done in the future (like move abroad or far away from my parents to work) I am less likely to do. My brother has changed my life in a very positive way, as our family is close, and I have a very close relationship with my brother. He makes me really happy to be around him."



The Quintella Girls

Online Support and e-mail Lists

Sibs Encounter: Online support group for brothers and sisters of people with disabilities, www.sibspace.org

SibKids: Yahoo e-mail list for the siblings of children with special needs worldwide (managed by The Sibling Support Project), <http://groups.yahoo.com/group/SibKids/>

SibNet: Yahoo e-mail list for and about adult siblings of people with special needs worldwide (managed by The Sibling Support Project), <http://groups.yahoo.com/group/SibNet/>

Useful Website

The Siblings Support Project (USA):
<http://thearc.org/siblingsupport/index.htm>

Literature

Meyer, Donald J., ed. *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs*. Woodbine House, 1997. ISBN 0933149980.

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Tozer, Rosemary. *Brothers, Sisters and Learning Disability: A Guide for Parents*. BILD Publications, 1996. ISBN 1873791879.

Gans, Lydia. *Sisters, Brothers, and Disability: A Family Album*. Fairview Press, 1997. ISBN 1577490444.

Flynn, Margaret and Peter Flynn. *Think About - Having a Learning Disability*. Belitha Press Ltd. ISBN 1855618079.

**Thank you to the Down Syndrome Association for permission to reprint this.*

Remember: *The DSCBA has sibling support available in groups and individual counseling. We will also set up social groups such as bowling, etc. Call the DSCBA at 925-362-8660 for more information.*

New Year's Resolution #1

BECOMING EDUCATED ABOUT MY CHILD'S COMMUNICATION RIGHTS AND NEEDS

Heather Peterson, MS, SLP-CCC

Happy New Year! Make it your New Year's resolution to fight for your child's voice.

Please familiarize yourself below with the rights and needs of your child regarding communication.

- 1) **If your child is three years old or younger**, contact your local Regional Center and request speech and feeding therapy. Typically regional centers begin traditional speech therapy at 18 months of age; however, many of our children have the potential to imitate and create speech sounds earlier than that, especially if they have received sensory-motor feeding therapy. Feeding therapy should be requested if your child is having trouble latching, pacing, or taking the correct amount of milk necessary for their age. It is my personal experience that all of our babies can benefit from facial and oral stimulation techniques to help with feeding and speech musculature development. This leads to increased strength, stability, and mobility in the jaw, lips, and tongue for creating speech sounds and proper eating patterns.
- 2) **If your child is between three years and kindergarten age**, please contact your local school district and have your child evaluated in order to start receiving free speech and language therapy from the school district. School providers can be great at building your child's speech and language skills. Providers don't like targeting the same exact thing every day, and neither do you, so send a small spiral notebook and a folder in your child's backpack and kindly request that your providers update you and send homework home to practice. This will increase your child's progress on their goals! It will make everyone feel more connected and part of the team. Homework should be practiced three to five times per week in order to see the skills generalize. Sensory-Motor/Oral Placement evaluation is strongly recommended. (<http://www.talktools.com/find-a-therapist/>)
- 3) **If your child is school aged**, please connect with your school provider so you can be doing homework three to five times per week. Also you should connect private and school therapists to consult about your child's goals. It is okay for private providers to target specific areas like feeding and articulation therapy (oral placement therapy/sensory-motor) while school providers target language and functional speech in the classroom. This is also a good age (if not earlier) to be looking into Alternative and Augmentative Communication (AAC) for your child. These devices can be as simple as communicating with pictures. They can be high tech like a personal electronic device. It is your right to ask for an AAC evaluation from your school district (it is different from a speech and language eval). It is a common trend that our kids are slower to develop expressive speech than their receptive language. It is our job to fight for their voice. A total communication approach can be wonderful and can be a bridge to verbal language.
- 4) **If your child is over 10 years of age** and you feel like their speech and language goals have either stayed the same for the past few years and/or the school is recommending less speech and language therapy on the IEP, fight to keep the time you have and reach out to a local Oral Placement Therapist (<http://www.talktools.com/find-a-therapist/>) who will help you to build stability in your child's mouth to move you forward in your child's speech clarity goals. Please also see the AAC recommendations above.
- 5) **If your child is an adult**, it is never too late to work on speech clarity and language surrounding activities of daily living. In my experience, adults and even teenagers have developed some great self-motivation and often learn new skills quickly when they feel it is important to their jobs, social lives, dating lives, etc. Finding a private speech therapist that specializes in the area you want to target would be a great place to start.

Good luck with your New Year's resolutions!

Please contact me with questions. Heather@happykidstherapy.com or 202-425-6874

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

Foundations, Family Funds, and Service Organizations

Maurice Amado Foundation
 Anonymous Family Foundation
 Barr Family Foundation
 Ray Benton Family Fund
 Calhoun Family Fund
 California Communications Access Foundation
 The Columbus Foundation
 Diablo Country Club Foundation
 Carl Gellert and Celia Berta Gellert Foundation
 Global Down Syndrome Foundation
 National Down Syndrome Congress
 Heffernan Group Foundation
 Jam Handy Character Building Foundation
 Kiwanis Club of Pleasanton
 Kiwanis Club of San Ramon Valley
 Knights of Columbus Council 9206, San Ramon
 Lencioni Family Fund
 The Joseph and Vera Long Foundation
 The Thomas J. Long Foundation
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 Peter Musto Charitable Trust
 NAILBA Charitable Foundation
 Noll Foundation
 Quest Foundation
 San Ramon Rotary
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 Wells Fargo Foundation
 Whole Foods – San Ramon

General Donations

The Alfrey Family
 Benjamin and Kay Andersen
 Nancy Baptist and Pat Katavich
 Chris Bruno
 Richard Buziak
 CAHN on behalf of Eric Tang
 Ron & Julie Casadont
 Cavu Wealth Advisors
 The Del Amigo Pool Swimathon

Lorraine and Lawrence Delia
 tanjali Magodia
 Girls Scouts of No Cal Troop 30677
 Arthur and Jane Hillman
 Jeanne & Steve Karabin
 Kids N Need/Elliott's Golf Tournament
 Chris LaBelle
 Julia Laudencia
 Martha Loera
 Nancy & John O'Rourke
 St Joan of Arc Youth Ministry
 Amy & Thomas Souza
 The WGA Golf Tourney Woman's Group
 Shirley Wilson

Agilent Technologies Foundation

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Community Health Charities of CA

Judy L. Hawkins

Kaiser Community Giving Program

Wanda Haskell
 Richard LaBelle

Microsoft Matching Gifts Program

Howard L. Cooperstein

In Memory of Gina Covelto

Joseph and Carolyn Covelto
 The Covelto Group

In Memory of Robert Fosket

Martha and Kevin Hogan

In Memory of Fred Jacobs

Martha and Kevin Hogan

In Honor of Sam Jones

Edwin and Josette Ogan

In Honor of Heather Peterson

Lorin and Ila Peterson

In Honor of Ian Andrew Randick

Robert and Marlys Randick

In Memory of Mark Rettig

Nick Smyth and a crew of folks Mark worked with
 Rosemary Cannon
 Marian Checchi
 Kathleen & Donald Deregó
 Johan & Sharon Dufrane
 Karen Ahrens
 Paul Rettig
 Mary Ann Dong
 Pat Occasion

Mary Louise Guttman
 Mark Silva

In Honor of Jason Roysdon's Birthday

Kathy VandenBerghe

In Honor of Kate Roysdon's Birthday

Kathy VandenBerghe

In Honor of Kristian Rumney

The Greenbrier Middle School

In Honor of Kathy VandenBerghe's Birthday

Victor VandenBerghe

In Honor of Ron & Patty VandenBerghe's 55th Wedding Anniversary

Victor and Kathy VandenBerghe

In Honor of Victor VandenBerghe's Birthday

Kathy VandenBerghe

In Appreciation of Ron & Patty VandenBerghe

Kathy & Victor VandenBerghe

In Appreciation of the DSCBA Staff

Kathy & Victor VandenBerghe

Blessing to Mark, Cathy, Melanie & Luke VandenBerghe

Kathy & Victor VandenBerghe

In Honor of Mason Zolnier

James and Kathy Zolnier

In Memory of Cornelius Cassimere

Victor and Kathy VandenBerghe

In Memory of Robert Matthew Gillin

Sue Cooley

In Memory of Susannah Richman

Harriet Frankel

Speech Therapy Scholarship Fund

Steven and Mary Joyce Duchene

VOLUNTEERS

2012 Step Up for Down Syndrome Walk Volunteers

Kayla Andrews	Linda Jones
California High School Leadership	Jo Kelley
Tami Castelluccio	Rich Kelley
Judith Clark	National Charity League,
Maureen Cummings	Diablo Valley Chapter
DSCBA Board & Staff	National Charity League,
Jane Fountain	Rolling Hills Chapter
Brian Garcia	Laura Redmond
Tammy Garcia	Trevor Robb
Terese Ghilarducci	St. Joan of Arc Light Youth Group
K.C. Hogan	Lisa Upton
Camille Hunt	Valley Cheer and Dance
Morgan Jimenez	Jennifer Van Blair

2012 Holiday Party Volunteers

Izzy Affolter	Madison Ferguson
K. Leigh Alfrey	Taylor Fink
Conner Anthony	Maddy Henry
Hannah Bornstein	Marie Jimenez
Jennifer Bornstein	Morgan Jimenez
Brownie Troop, Pleasant Hill	Jimmy King
Mike Cannon	Kathy Klimacki
Cristyn Carlson	Macee LeMoine
Tami Castelluccio	Mistry Family
Marian Catedral-King	National Charity League, Diablo Valley Chapter
Olivia Dadgari	National Charity League, Rolling Hills Chapter
Gloria Delrio-Casadont	Cari Newbrand
Mike DeMasi	Nicole Patton
Hannah Dillon	Megan Portoni
Theresa Dillon	Phyllis Roach
Danyella Duran	Lisa Upton

Dedicated Classroom Volunteers

K. Leigh Alfrey
 Tawny Burns
 Lindsay Dobbs
 Wendy Earl
 Brian Fruchey
 Dawn Handley
 Camille Hunt
 Macee LeMoine
 Alexis Liebowitz
 Elyse Perry
 Laura Redmond
 Paula Ridley
 Lynn Sanford
 Logan Silliman
 Carolyn Tse

— Upcoming Events —

March 9, 2013 – 2nd Annual DSCBA Empowerment Conference, see below

April 7, 2013 – DSCBA Bowling for Dollars, see page 13

May 4, 2013 – Annual Gala for Giving at the Diablo Country Club, see page 18



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2nd Annual

Save the Date

DSCBA Empowerment Conference & Annual Meeting

Saturday, March 9, 2013 • 8:30a.m. – 4:00p.m. • Rolling Hills Community Church in Danville

This conference will provide education and practical advice to empower DSCBA members and Bay Area educators – Don't miss it!

Keynote Speaker Mike Machado

Mike is the Varsity football coach at Valley Christian High School in San Jose and founder of Football Camp for the Stars. Coach Machado created the camp to honor the contributions of his team manager Andrew Watson, who has managed the Valley Christian football program for 15 seasons and who just happens to have Down syndrome. "He's been leading our team out to the field, but then goes back to the sidelines to root the team on from there," Machado explained. "I wanted to create something where he was going to be the guy out on the field, it was going to be about him and he was going to be the star for once." "The program also helps educate the general public about Down syndrome."

Experts will speak on these topics

- Know your Regional Center (ages 11+)
- Know your Regional Center (ages 0 - 10)
- All About Sensory
- Negotiating a Great IEP
- Transitioning – High School to 22
- From Grief to Celebration
- Communication Systems for the Classroom
- Behavior is Communication

Excellence in Education Award

To nominate an educator, administrator, bus driver, paraeducator etc. please send an e-mail to dscba@dsconnection.org with the following information: Your name, email, phone, students name and age – nominee's name, school, title, phone and email. Include a paragraph answering this question; How has your nominee made a significant difference in your child's education experience? We will choose 2 recipients to receive acknowledgement at the conference. The rest of your nominees will be sent a certificate of appreciation with your story so send them ALL in.

CHILD CARE WILL BE AVAILABLE FOR MEMBERS ONLY - DETAILS TO FOLLOW

Fee: \$25 per person or \$40 per couple – Includes education, breakfast and lunch, and childcare – Watch for registration forms in your mailbox and online registration in late January.