



# Making the Connection

SUMMER 2012

DOWN SYNDROME CONNECTION OF THE BAY AREA

## Fourth of July

*Heather Peterson, MS, SLP-CCC*

After four years of being involved with the Kiwanis Danville July 4<sup>th</sup> Parade and float-building experience, I genuinely felt that this year was the best! Everything felt right. Thank you to the Crawford family and to *Unique Elevator Interiors*, who generously donated the flatbed that allowed us to create a great float. This year's theme was "Danville, Small Town Values—Big Heart." It was great fun to apply papier-mâché to the famous *Danville Oak Tree*, which represented our small town. Once again, we could count on handyman extraordinaire and all-around great guy Rich Kelley to build our float with an amazing tree and to drive it proudly in the parade. For the big heart concept, we honored our funders on hearts lined along the sides of the float to show our appreciation for their continued support of our mission. Many parents came out for the first time and, as you can see from the photos, everyone created their own T-shirt masterpieces to wear in the parade. Thank you to Julie Manning for creating the float concept this year and to Brian Garcia for his dedication to the day's event. A shout-out to the Kelleys for opening their home and to everyone else who attended the float-building party. Kudos to Gloria Casadont, Conner and Peggy Alreck-Anthony, the Azzopardi family, and Sam Kelley for decorating the most creative T-shirts! A special thank you goes to Board Member Karen Lochner for her support.

Thank you to the San Ramon Kiwanis for hosting this wonderful community event each year. As always we are hopeful to win the community service float award. Fingers crossed—we are two for three so far! *More photos, page 2*



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## New Web Site for the DSCBA Is Here!

We are excited to say we have a new Web site under construction. This Web site gives us the flexibility to change and add things as needed without cost to the organization. Another cool thing is the Google Select Language feature. Choose a language from a menu and the entire Web site converts to that language. We have a great slide show on the Home page as well as the ability to add videos and photos anywhere. There is a new area called Professionals and Educators. This page will hold information for educators and therapists who work with your children every day and who have committed to working with us via our Down Syndrome Educational Alliance program. We have a calendar to easily find events, classes, workshops, and support groups. Coming in phase two will be the ability to register for classes, workshops, and more, right on the site. We hope you enjoy the new Web site. We are always open to suggestions on how to make it better and of value to everyone.







# Down Syndrome Connection OF THE BAY AREA

## Terese's Tales

Terese Ghilarducci, President of the Board

### Board of Directors – 2012

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Tracy Trotter, MD, Pediatrician  
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### Down Syndrome Connection of the Bay Area

www.dsconnection.org

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### Board Meetings – 2012

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

The Board meets on the 3rd Tuesday of the month: Jul. 17, Aug. 21, Sep. 18, Oct. 16, Nov. 20, no Dec. meeting. To attend or bring a guest please call the Board President, Terese Ghilarducci at 925-872-5858.

### DSCBA Staff

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### 2012 Parents Support Group\*

See page 22 for schedule

Parents of children with Down syndrome are welcome and encouraged to join our monthly support group to exchange information, share common experiences, and be encouraged by other parents with similar issues and concerns. The group meets at the Danville Connection office, 101 J Town & Country Drive. Please call Martha Hogan if you have questions or to tell her you are coming: (925) 362-8660.

\*Child care is not available.  
Babies under 10 months are welcome.  
This group is for parents.

Happy summer to all! Summer brings such fun times with swimming, barbecues, vacations, and time off from work and school. I hope you are all enjoying this fabulous time of year. At the Connection, we are as busy as ever. As you can see, we celebrated the Fourth of July in style. Our float was wonderful thanks to the hard work of Rich Kelley and Heather Peterson, who organized the event. Our goal is always to promote Down syndrome awareness and to show our community how “connected” we are to all people, no matter what our disabilities.



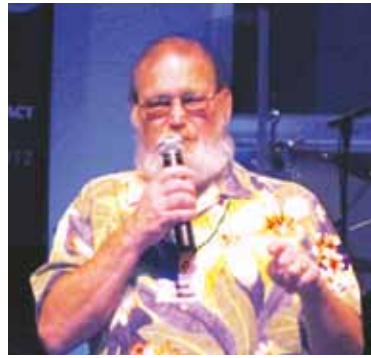
Get ready this summer to build your web pages and send them to everyone you know for another (fun) raising experience at the Step Up for Down Syndrome Walk on Sunday, October 7, 2012. We can't wait to have a lot of fun walking, eating, playing games, and enjoying each other's company at the Little Hills Ranch in San Ramon. For all of those who were there last year, you know what a fun-filled day it was. We know we are going to have another successful event this year. Get your walking shoes ready!

I also want to take this time to thank our staff and members who participated in our First Annual DSCBA Empowerment Conference on March 17, 2012, and our annual Gala for Giving on May 5, 2012. I have so many wonderful memories of both those events: the first being the amazing educators who received awards at the empowerment conference for making a difference at school for our children. Since I worked as a full inclusion aid in the San Ramon Valley School District back in the 1990s, and given my current work in education, I was especially proud of the work by our honorees this year.

The annual Gala for Giving held at the Diablo Country Club was a beautiful, magical night with dinner, dancing, and amazing silent and live auction items up for bid. I even got a chance to bid on some silent auction items and went home with a basket of goodies. I know everyone there had a great time; I want to thank our volunteers from Circle K as well as the committees led by Jennifer Bornstein and Jo Kelley. Nancy and the staff put in countless hours of work to make this event such a success. We are happy to have Kathy Harkins back at the Connection; she is helping out with event administration.

Lastly, I want to thank Martha, Nancy, Kathy, Marianne, and Jennifer Cooper for organizing the Down Syndrome Educational Alliance kick off at the Diablo Country Club for educators around the Bay Area. We hope to get as many educators as possible to become Down Syndrome Specialists so that our children and adolescents can have the best school year possible coming up in the fall.

As always, thank you for letting me be your president, and I will see you around the Connection.



Top left: The UC Berkeley student volunteers  
Above: Dr. Frank Marone, PhD, BCBA



Above: Bubbles are in the air

At left: So many toys are wonderful!

Far left: Circle time at child care

## First Annual Empowerment Conference and Annual Meeting—A Great Success

**Nancy LaBelle**

Thanks to everyone who attended our first empowerment conference and Annual Meeting on St. Patrick's Day this year. It was our first attempt at creating a conference environment and agenda focusing on empowering our parents, and we hope you enjoyed the day.

After situating the participating kids in child care with UC Berkeley student volunteers and their siblings into Sibling Support and Music Therapy, we were ready to roll. The day started with my welcoming all attendees and guests. Terese Ghilarducci, our Board President, went on to introduce the current Board of Directors and made a motion to our members to approve them for the year 2012. We then presented Excellence in Education awards to educators nominated by our parents. Four schools were submitted, and 11 educators received a certificate of appreciation after parents read their nomination to the crowd.

The rest of the morning was a presentation for everyone on behavior, followed by a question and answer session that was very popular during lunch hour. After lunch we moved on to our breakout sessions. We wanted to have something for everyone at this conference so we chose a panel of experts to address communication skills and another for adult services. At the communication session, parents learned information on oral motor skills, dental health, augmentative and alternative communication, and sign language and hearing issues. The panel for adult services discussed conservatorships, transition and adult programs, and services for adults.

### **Thank you to our speakers who attended and delivered great information to our families:**

- |   |  |
|---|--|
| Dr. Frank Marone, PhD, BCBA<br>– Applied Behavior Analyst   | Carol Gonsalves – Coordinator of Training, Matrix Parent Network and Resource Center |
| Heather Peterson, MS, SLP-CCC<br>– Speech Pathologist, Specializing in Oral Motor Therapy                       | Therese Bush – Case Manager, East Bay Regional Center                                |
| Dr. Brian Hockel, DDS – Specializing in the Unique Dental Needs of People with Down Syndrome                    | <b>Special Thanks to:</b>  |
| Kati Skulski, MS, SLP-CCC<br>– Speech Pathologist, Specializing in Augmentative Alternative Communication (AAC) | Our friends at the Rolling Hills Community Church, Danville                          |
| Carol Lettko, MS, SLP-CCC – Speech Pathologist, Center for Early Intervention on Deafness (CEID)                | Terese Ghilarducci, MFT<br>– Sibling Support   |
| Debra Wilhelmus, Esq<br>– Attorney, Special Needs Trusts and Conservatorships                                   | Nicole Patton<br>– Certified Music Therapist   |
|   | Laura Redmond and the UC Berkeley volunteers   |
|   | The DSCBA Staff  |
|   | The DSCBA Board of Directors   |
|   | Gagnon's Catering  |

**Our next DSCBA Empowerment Conference and Annual Meeting** will be held on Saturday, March 9, 2013, at the Rolling Hills Community Church. Please **save the date**. We are open to suggestions for topics and speakers. Please call Kathy Harkins at 925-362-8660 or email her at [Kathy@dsconnection.org](mailto:Kathy@dsconnection.org).





## Sibling Support at the First Annual DSCBA Empowerment Conference

*Terese Ghilarducci*

This year we had our first annual empowerment conference. For those of you who attended, I hope it was an educational, fun-filled day for you. I had the pleasure of working with 8 siblings and 1 uncle between the ages of 7 and 14 years old. I also had a helper, Stephanie Yu, from Circle K at UC Berkeley. The day was spent getting to know each of the children and teens. It was interesting to have the group pair off and conduct peer interviews with each other. The next activity was to make a family drawing, after which we talked about our feelings.

Common feelings about a brother or sister with Down syndrome are anger, sadness, frustration, guilt, and pressure to be perfect. In the work I have done with siblings over the past three years, the pressure to be perfect has come up often. Family members think that because they have a brother, sister, or nephew disability, they have to be perfect to compensate for their sibling and to relieve some of the stress their parents are already experiencing. It is important for parents to set reasonable expectations for all of their children and to reinforce the point that no one is perfect.

One of the group's favorite activities was to pick a question from "Aunt Blabby" and answer it as though they were advice columnists. Some of the older siblings in the group really wanted to say that they hate it when their friends or anyone uses the R-word: they want to get the message across to *spread the word to end the word*. When we talked about the R-word, some of the younger siblings started to laugh—which I believe is often a sign that they are uncomfortable with the discussion. Talk to your children about their feelings. If they aren't ready for a group or to talk about their feelings, then just leave the door open for a time when they may be ready. Some other sage advice from my group is to explain Down syndrome to your friends. If the friends are mean or tease your brother or sister, then don't be friends with them, because they aren't friend-worthy.

The final activity of the day was to write or draw their dream for themselves and their dream for their sibling or nephew. More than anything, the dream they have for their siblings is to be happy and successful.

I hope that I can be of help with any sibling issues that may come up in your family. Be sure to always talk to your children and teens and let them feel free to express themselves to you.

## Speaking of Apraxia: A Parents' Guide to Childhood Apraxia of Speech

*by Leslie A. Lindsay, RN, BSN*

**Book Review by Teresa J. Unnerstall**

Woodbine House recently published the first comprehensive guide for parents who have a child with Childhood Apraxia of Speech (CAS). CAS is a neurologically based condition that is characterized by difficulties planning and producing the complex set of oral movements necessary for intelligible speech. Determined to find out more and learn how to best help her daughter, the author started doing extensive research that culminated in this book containing the latest research written with an empathetic style.



Children with Down syndrome can also have CAS. This book mentions a study done by Dr. Libby Kumin that found 16 percent of the children with Down syndrome either had been diagnosed with CAS or had difficulties with oral motor skills. Even when the CAS diagnosis had not been given, the survey respondents often said their children were experiencing many symptoms consistent with CAS (most notably: more difficulty being understood than their peers with Down syndrome, sound reversals, and sound errors). The survey also revealed that children with Down syndrome and apraxia tend to begin speaking at a later age, around five years.

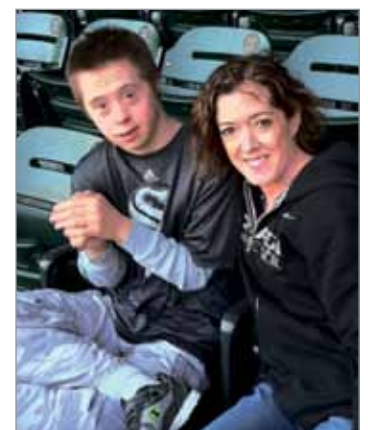
The book is organized with bullet points and succinct summaries that make it easy to see if your topic will be covered in that chapter. You can decide where to start and what to read. This guide offers real-world advice, tips, and plenty of ideas. All are practical, easy to implement, and work right into the daily schedule, whether you are at home, at a park, or simply driving in the car.

As a parent of a child with Down syndrome, apraxia, and autism, I appreciated the sections on how to cope as a parent. All through the book, the topics offered immediate references that directed you to find out more in other chapters. The book covers everything from what CAS is and how it is diagnosed and treated, to how to cope with CAS. It is loaded with resources in every chapter. This book is a must-have for parents, teachers, therapists, and medical professionals as a comprehensive guide that offers hope and practical advice relating to CAS.

Read more by Teresa Unnerstall at her blog: [www.nickspecialneeds.wordpress.com](http://www.nickspecialneeds.wordpress.com).



Above: Al, Nick, Hank, and Teresa Unnerstall  
At right: Nick and Teresa





## Oral Placement Therapy Spotlight

Heather Peterson MS, SLP-CCC

Many parents ask me, “When is the right time to start Oral Placement Therapy (OPT)?” The general answer is that you can always start OPT, age doesn’t matter. However, my more personalized answer always is, “When it is right for your family.” OPT is a commitment to work five times per week for 20–30 minutes per day. It’s a commitment to improve feeding skills and speech clarity. As with anything we do with our children, it takes time to establish routines and to change motor patterns and muscular structure. Here are some examples of families who have made a difference in their children’s lives, in various time periods and at different ages.

**ELLA:** Therapy Duration: 18.5 months, Age: 19.5 months

Parent Statement: Ella has made tremendous progress due to OPT. She started the program at five weeks old for tongue protrusion and a weak suck. Now she is 20 months old and her tongue is in about 85% of the time. She is saying “bye-bye” and “hi.” She eats everything: lettuce, kale, steamed vegetables, and stewed and BBQ meat. It’s a joke that we have about her. We have trained everyone who feeds Ella to do her therapy, which helps to divide the responsibility and to make it much easier to handle on a day to day basis. We can’t say enough good things about her progress!  
– Rachael Kriksciunas (mom)



Above, Ella at 6 months, and at right, 19 months

*Note from Heather:* It is a pleasure to work with a family who takes the program so seriously. Ella’s before-and-after pictures tell the story best. This is why Sara Rosenfeld-Johnson created this program, to give babies with Down syndrome the chance to develop just like a typical child. What an amazing start to a child’s life—stay tuned for more updates!

**AINSLEY:** Therapy Duration: 3 years, Age: 5 years old

Parent Statement: We worked for so long to get Ainsley’s bilabial sounds, /m, p, b/, that one day when she had her bilabial breakthrough in therapy, Heather and I were on the verge of tears. It felt like a switch finally flipped. That progress (“dede” now “baby”, “doo” now “moo”) inspires me to continue her program daily. We have used many behavior modification strategies such as play, food motivators, and activities like swimming as rewards for doing therapy. Time of day (morning is best) is critical. In the last year we have been able to utilize her cognitive development too. We can tell Ainsley to think about



what her lips are doing (lips together for “m”), and she corrects. Additionally, attending the Talk Tools conference and using the apraxia shapes in school was critical to her breakthrough!  
– Jennifer Dodge (mom)

*Note from Heather:* Ainsley and her mother, Jennifer, are incredibly dedicated to Ainsley’s speech clarity development. Ainsley, like many of our kids, has Apraxia of Speech and low muscle tone. She has worked diligently through the hierarchies of tools as part of the OPT programs. She has retracted her tongue, learned to eat beautifully, and now produces /p, b, m, n, w, h, g, k, A, E, I, O, U, ah, uh, oo/ sounds in consonant-vowel combinations. Additionally, she produces these sounds clearly and precisely with the correct mouth movement so that when we build on these productions they will remain clear. Ladies, we applaud you for your dedication!

**GABRIEL:** Therapy Duration: 3 months, Age: 9 years old

Parent Statement: I was reluctant to start OPT because I wasn’t sure how much time it was going to take and how consistent I was going to be. I’m glad that we started. Gabriel loves working with me, and his aide at school has commented that she can understand him more! I’ve also noticed that his oral awareness has improved because he is starting to wipe food off his face without us prompting him.



– Angie Rettig (mom)

*Note from Heather:* Years ago, Gabriel was using a typical speech program (imitation of mouth movements, use of the PROMPT method), and we failed to progress much over long lengths of time. This was very discouraging. Over the past few months we began using an OPT program with Gabe and have seen really quick progress. Gabriel has Apraxia of Speech and low muscle tone. He has trouble accessing sounds and also creating them using the correct mouth movements. With the consistency of a home program, Gabriel is quickly mastering consonant and vowel combinations that he previously had years of trouble producing. His /p, b, m/ sounds paired with some hard-to-produce vowels, /E, O, oo/, are looking fantastic. What a difference the right program has made for Gabriel!

Oral Placement Therapy Spotlight, see page 7





Oral Placement Therapy Spotlight, from page 6

**EMMA YUNGERT:** Therapy

Duration: 2 years, Age: 20 years old

Parent Statement: Emma Yungert is an energetic and determined young woman (who turns 21 in July!) who still has the drive and passion to work on her speech, among the many other activities in her life. Two years ago we began using the Talk Tools OPT program with Emma to see if we could improve Emma's articulation and intelligibility. We have seen wonderful improvement using this program three times per week. When family and friends comment that they understand Emma so much better, it makes us even more determined to continue. In July, when we attend the National Down Syndrome Conference in Washington, DC, Emma will have a two-hour speech evaluation with Sara Rosenfeld-Johnson, the creator of Oral Placement Therapy. Emma, Heather, and I are so excited to continue seeing even greater progress!



– Monika Yungert (mom)

Note from Heather: Emma is a shining example of a woman with internal motivation. When I met Emma, it was shocking to me that she lacked some very basic sounds in her conversational speech (d, t, s, w). It's obvious when meeting Emma that she is an intelligent and sophisticated woman; however, for 18 years she was misrepresented by her juvenile speech patterns. Emma has worked hard to learn a /d/ sound approximation and is currently targeting her /s/ and /s-blends/. Emma's jaw has become significantly more stable through our OPT program, which has increased her overall intelligibility greatly. Happy 21st birthday, Emma!

**League of His Own**

**Shelli Rhodes**



Troy Rhodes is in a league of his own, literally. Troy is six years old with Down syndrome and is the first participant in West Coast Soccer Club's program for special-needs children, We Can Soccer. Soccer gives the benefits of physical activity, being part of a group, learning social skills, and, of course, having fun. The We Can Soccer program is open to players of all ages and all disabilities. Since he was

first on the team, a couple more kids with Down syndrome have joined the team.

Troy loves to kick the ball, and in his first game he scored a goal. Since he was the only one, he just played with all the other kids. They really greeted him warmly—a very welcoming atmosphere with the kids and the parents. One of the ideas for We Can Soccer is for family members to play on the same team. Instead of siblings watching each other, they can play together, wear the same uniform, and learn the same skills, at different levels. For more information, please see [wecansoccer@westcoastsoccerclub.com](mailto:wecansoccer@westcoastsoccerclub.com).

Above, Troy, in uniform, below, on the field



**Martin's Own Home**

**Carol Gonsalves**

In March, Martin Gonsalves, 28-year-old Benicia Step participant, moved into his own home after two and a half years of planning. Martin lives in a one-bedroom condo in his hometown of Benicia. He enjoys living in, as he says, "my house" where he actively participates in all household tasks with support from Supported Living Services. He has already hosted two housewarmings and two barbecues with friends. His condo is decorated with memorabilia of Bruce Springsteen, oldies, and The Three Stooges. Martin has adapted well to the move out of Mom's house—probably better than Mom has! Over the past three years, Martin has worked hard at learning to grocery shop, cook dinner, bank, and take care of other personal responsibilities, including a lot of self-care for his type 1 diabetes. With his amazing personal assistant and good friend Jenni, Martin has achieved so much more than anyone thought possible. Hurray, Martin! And here come those summer barbecues.



Above, Martin in his apartment with his favorites, The Three Stooges



Martin with Andrew Vasquez



Martin shows Lisa Silva his new washer and dryer



Martin's housewarming party



Major and Mason

## Welcome, Major

Congratulations to Board Members Mike and Karen Zolnier and big brother Mason! They welcomed Major Alexander Zolnier on Valentine's Day 2012. Major weighed in at 7 pounds, 4 ounces and measured 20 inches.

## Congratulations, Caleb

*Esther Chow*

Big congratulations to Caleb Chow for his graduation from Alameda High School! Caleb received two awards: Honor Roll and Success at Work. In addition, he performed a solo dance he choreographed and several group dances with his Contemporary Dance class on June 7, 2012. Bravo, Caleb!



## New Information Forum

*Meriah Nichols*

The International Alliance of Writers for Down Syndrome has been formed on the Web site at

<http://t21writers>

[alliance.blogspot.com/](http://alliance.blogspot.com/). It is a forum for blogs, posts, book reviews, and a repository of other written information related to Down syndrome and advocacy. There is an extensive blog roll. Please submit your own blog, articles, or book reviews related to Down syndrome to [t21alliance@gmail.com](mailto:t21alliance@gmail.com).

In addition to the Web site, there is an active T21 Alliance of Writers group on Facebook at <http://www.facebook.com/groups/t21alliance>.



Moxie

## Down Syndrome Educational Alliance Launches in Bay Area Schools

*Nancy LaBelle*

I am excited to say that on April 27, 2012, at the Diablo Country Club, the Down Syndrome Connection of the Bay Area (DSCBA) introduced the Down Syndrome Educational Alliance (DSEA) program to 35 Bay Area school educators, administrators, principals, and therapists who represented 13 school districts.

The primary focus of the DSEA program is to build a collaborative relationship between the DSCBA and school districts to ensure positive outcomes for students with Down syndrome. The program asks that a school district name a volunteer Down Syndrome (DS) Specialist, and, in return, the DSCBA commits to being a point of contact, providing training, and developing and delivering resources to every DS Specialist. There is no cost to the school district to join this program, and the DSCBA will be seeking grants to keep it going strong.

I recognize that over the years we have focused the majority of our efforts on supporting, training, and educating parents of children with Down syndrome. I believe we must now also focus on serving educators and therapists as they have a profound impact on individuals with Down syndrome achieving their potential.

Based on the information we hear from both parents and educators, we know students with Down syndrome are in classrooms with educators that have received little or no specialized training in teaching methods proven successful for their students' unique learning needs.

At the end of 2011, I got in touch with the Down Syndrome Guild of Greater Kansas City who launched this program eight years ago. I was delighted to know this partnership program has been modeled successfully in 10 states across the country. After spending a considerable amount of time understanding the impact to our organization and the profound impact this can make for children of all ages in the school system, the staff at the Down Syndrome Connection is proud to be the first organization to launch this program in the state of California.

The DS Specialist will have direct access to the DSCBA staff via phone or on-site, as well as to the lending library, the augmentative

alternative communication device library, and to professionals in the field of behavior and communication. At the first training session, to be held in September 2012, a flash drive loaded with tools and materials that focus on how to teach children with Down syndrome to their full potential will be given to each educator. In September, educators committed to this program will learn everything they need to know about Down syndrome: what it is and isn't, strategies for teaching to potential, and the benefits of an inclusive environment.

I will also be creating a quarterly e-newsletter called "The Bridge" that will be offered to districts who participate in the program. The Bridge will contain current information about Down syndrome, best practices, research, and links to education materials. Our new Web site also has a dedicated area for educators and therapists, ensuring that materials are easily accessible.

We believe that through this alliance program the DS Specialist will be able to share specific information about Down syndrome and educational methodologies with peers. The Specialist will also be able to report patterns of behavior and/or learning challenges that are common to children with Down syndrome to the DSCBA so we can suggest or develop appropriate interventions.

The DSCBA staff had no idea how this would go over with the districts attending the luncheon. We were excited that seven school districts signed up without hesitation at the launch or shortly thereafter.

Thank you to the community and our members who gave so generously to this program at the 2012 Gala for Giving. We raised \$14,000 during a *Fund a Need* auction to put time, materials, and love into making this a success.

We now have 17 DS Specialists from 11 unified school districts and 2 private schools who are committed to working with the DSCBA in the following areas:

- Dublin • Benicia • Berkeley
- Brentwood • Pleasanton
- Lafayette • San Ramon Valley
- Fremont • Antioch • Albany • Livermore
- Noah's Arc – Danville Private School
- Big Valley Christian – Modesto Private School





Daniel Sodestrom and Lexi Liebowitz



Laura Redmond, Macee LeMoine, and Lauren Bruno with Tatiana Casadont



LuLu Jensen, Elyse Perry, and Haley Wollesen



Cole Kelley and Andreas Dereschuk

## We Love Our Volunteers!

### Marianne Iversen

We are so fortunate to have such amazing and dedicated volunteers. In April, during National Volunteer Recognition week, we honored our classroom volunteers by holding a dinner at the Prickly Pear Cantina. We had a wonderful time getting to know one another better. We were so happy to have the opportunity to let these incredible folks know how much they are appreciated. Volunteers give of themselves every week and serve as wonderful role models and peers to our class participants. Several of our volunteers have been with us for over three years; their dedication does not go unnoticed by all of the staff and parents here at the Connection. Best wishes go out to Andreas Dereschuk, Loren Bruno, Matt Duckett, and Sean Duckett, who will be going off to college this coming fall but promise to come by and visit when they are home.



Camille Hunt

## Karina's Night in Paris

### Cora Bengco-Friederichs

My daughter, Karina Rose Bengco, was invited by her boyfriend, Mario Arrizon, to his Senior Ball at California High School, where the theme of the Ball was "A Night in Paris." Yes, my princess and her Prince Charming went to "Paris". It was a night to remember.



Karina and Mario

All the girls looked so beautiful in their gowns, and the boys looked so handsome in their tuxedos. The school's principal and teachers were so happy to see Mario and Karina, who were the only special-needs kids to attend the event. Their teacher, Mr. Ryan Kral, requested a slow song so they could dance. The dance floor was packed while Prince Mario and Princess Karina danced under the Eiffel Tower. It was so beautiful, so romantic, so sweet, and so loving. Thank you Cal High for allowing us to chaperone our kids; for awhile, we felt like we were in high school again.

## Chelsea's Quest to Be the Best

### Can you help?

### Lisa and Ray Werner

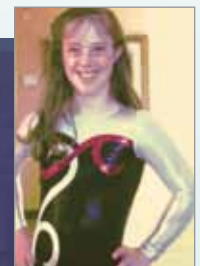
Chelsea Werner has just returned from the USA Gymnastics Special Olympics Championships in Atlanta, where she won four Gold Medals, including the All-Around, and is the two-time defending U.S. Champion.

In September 2012, she hopes to return to London for the World Championships.

Chelsea has also been invited to South Africa to participate in the Gym for Life World Challenge in the summer of 2013.

If you would like to donate to help Chelsea in her quest, please make checks payable to "Chelsea Werner" and send them to 3659 Country Club Terrace, Danville, CA 94506. Lisa and Ray, the proud parents, thank you.

For additional information please call or email: (925) 858-7399 [ChelseaQuest@yahoo.com](mailto:ChelseaQuest@yahoo.com).





## Tattoo Honors Brother

**Alex Ferguson**

I had wanted to get a tattoo for a long time with something to signify how Adam has changed my life in a positive way, by helping me become the person I am today. The Down syndrome ribbon seemed like the perfect way to do that, and putting the initials transformed it into something more personal.

Brothers Alex and Adam



Above: Alex's tattoo honoring Adam



## Rachael's Day as a Cowgirl

**Natalie Burbach**



The Livermore Rodeo comes to town the second weekend of every June. They have an exciting program called Lil' Partners for our children. This was our first year to attend, and Rachael loved it. Every child was paired up with a real cowboy or cowgirl and was escorted around to different stations: horseback riding, barrel racing with stick horses, hand-rocked bull, and a few other fun activities. Then all of the children were given a trophy. It was Rachael's first trophy,

which she was very proud of. They treated each child with such love! There had to be 100 volunteers, all of them delighted to be with our children. We even met the rodeo princesses. It was such a great day!

Check out the Livermore Rodeo Web site next year in May to sign your child up for this wonderful experience.



## Oliver Moves on to Kindergarten

**Nada Nakahara**

Right, Oliver receives his certificate for preschool from his fabulous teacher Joanne at the Albany Children's Center.



Left, afterward, Oliver enjoys a celebratory froyo at his favorite froyo spot, As You Wish, in Albany.



## Football Camp for the Stars

**Kathy Harkins**

Thanks to the Mariucci Family Foundation for sponsoring the 2012 Football Camp for the Stars! The camp is for young men with Down syndrome who love football. The staff includes the head football coach at Valley Christian, current and retired NFL players, NFL coaches, and college and prep school coaches. Blair, Andrew, Patrick, and Adam were lucky enough to be chosen to attend this two-day camp at Valley Christian Schools San Jose. The athletes learned the basics

of football, ran drills, learned techniques, and played in a scrimmage that was officiated by NFL referees. Slacking off was not allowed—there was no coddling of the campers. It was hard work, but what an amazing experience: our guys were the stars of football.

This magical camp changes the lives of all who give their time and love to be with our guys. The gentle giants (as we call the professional football players) give back to those of us

who have not been born with their athletic abilities. Some quotes from the NFL players are as follows:

"We have been to and participated in many camps and speaking engagements, and this experience has truly been the best experience of all."

"Knowing and working with these campers has changed my life forever."

"Never underestimate the power, determination, and abilities of these precious men." *Football, see page 11*







## Spread the Word to End the Word at UC Berkeley

Nancy LaBelle

Laura Redmond, a UC Berkeley student, a DSCBA volunteer, and a special friend of the Connection, organized a Spread the Word event on March 7, 2012, which was the official Spread the Word day! Laura said, "The R-word is used all too frequently, and it is very disheartening to me." At the DSCBA, we didn't have any doubt that the event was going to be organized and well thought-out by Laura—and when Marianne Iversen and I arrived, it surely was. It was an emotional and powerful day to make change at the campus. Everyone had a chance to sign a pledge to stop using the R-word, promoting acceptance of all. There were games and fun things to do to draw the attention of those on campus. End the R-word flyers and wristbands were handed out. Carnival-style games like "shooting the R-word" with a water gun were a lot of fun, and Laura had prizes ready to give out. At noon, we hit the Sproul Plaza to speak to the crowd hanging out for lunch. The Cal band came out for the event and played several uplifting tunes. Eli



Showing respect



Leah advocating for change



Taking aim at the R-word



Nancy's pledge



Speaking at Sproul Plaza



Marianne's pledge



Eli and Laura

Cooper and his friends spoke about the use of the word and how hurtful it is to not only Eli but to everyone with a disability. Leah Quintella, as you can see from her picture, was our biggest advocate that day as she held the sign

proudly; in fact, she did her best to make sure everyone saw it.

Thanks to everyone that came out to Berkeley in support of all the amazing people who deserve the R-word: RESPECT!

Football, from page 10

"This is so fun. I will be here for years to come."

"I love these guys: they give so much more to us than we can ever give back to them."

Other volunteers at this extraordinary camp include buddies for all the players, cheerleaders from the high school, and local fire and police departments.

At the Football Camp for the Stars, the athletes are the stars. All egos are put on the sidelines. Please enjoy the pictures from camp as they really tell the story.

The proud moms are Nancy Ferguson, Kathy Harkins, Martha Hogan, and Melody Vasquez.



### Private Music Therapy Sessions Available



Nicole Patton, MA, MT-BC has been providing private and group music therapy services for DSCBA families for 12 years. She is currently offering individual music therapy sessions in Danville. Nicole has over 20 years of music therapy experience working with children and young adults and is board certified with a master's degree in Special Education.

Many goals and objectives can be addressed through the use of music therapy in a fun, relaxing, and non-threatening atmosphere. Nicole utilizes IEPs and IFSPs, as well as parental input when planning sessions. Music therapy can address the following areas: personal, social, academic, speech, and occupational and physical therapy, as well as attention span and focus.

For more information about this opportunity, please phone Nicole Patton at 925-984-3263 or email her at [mrsmusic@mac.com](mailto:mrsmusic@mac.com).





★ ★ ★ ★ ★ ★ ★ ★ ★ ★ 2012 Gala For Giving ★ ★ ★ ★ ★ ★ ★ ★ ★ ★





## Gala for Giving

*Janet Richman*

On a beautiful May evening, my husband and I were dressed in our finery, driving to Diablo Country Club on our way to the Gala for Giving. We snaked our way along the lovely lanes lined with magnificent homes behind a line of cars heading to the same gala. We all stepped out, glittering and polished, and handed our keys to the nice young man who would park our car for the evening. As we checked in, giving our names and receiving our table assignment and program, I glanced around and saw some familiar faces. Everyone was sparkly and stunning in their evening attire.

Walking through the doors to the silent auction was dazzling. There were so many items to choose from—and so many, many people.

Wait. Stop. Was I dreaming? This was a fundraiser for the Down Syndrome Connection and it was so, well, fancy. This wasn't the fundraiser for the

*Gala, see page 14*







## Great Learning Game – bambinoLUK

**Laurie Hawley**



**Liam, playing and learning  
Inset, the game board**

I wanted to share one of the learning games we gave Liam for Christmas and have been working on with him: the bambinoLUK Early Learning series. A friend told me about it. Her son has Down syndrome and had a dynamic cognitive assessment done last summer by a team from the International Center for the Enhancement of Learning Potential from Israel. This is one of the activities the team recommended she do with him. I found it on Amazon.com and ordered the bambinoLUK Starter Pack and the SpecialLUK booklets to go with it.

The bambinoLUK system is designed to improve memorization, concentration, visual perception, logical thinking, linguistic skills, and basic math through play. It contains a puzzle-type game of six tiles with a series of workbooks targeted for children’s intellectual and developmental growth. It is geared for ages three to five (typically developing). They have three workbooks for children ages two and older: the SpecialLUK Primary Set, which is also recommended for children with special needs. Liam, age six, flew through the SpecialLUK workbooks. For his birthday in April, he got the “bambinoLUK Brain Training Early Bloomer Collection Set 1,” which is right at his level. They also have another series called miniLUK for older or more advanced children.

I like this program because it does not require any speech and needs very minimal fine motor skills—both of which can be learning stumbling blocks for our kids with Down syndrome. I also really like that it is teaching some very important cognitive skills such as scanning all the answers to find the best one (reducing impulsiveness), attention to detail, compare and contrast, checking your work, etc. One of the greatest improvements I have noticed in Liam from playing these games is that he has begun to self-correct. At the beginning, when he made a mistake he wouldn’t notice, or if he did he didn’t care. But now, as long as I resist my urge to correct him as soon as I see him make a mistake, he will usually catch it himself and fix it! It is nice that even though the activities change with each workbook page, the tiles you use to do the activity and answer the questions are always the same, and the routine is always the same.

It is difficult to describe the program in words, but the Web site, [www.luklearningsystem.com](http://www.luklearningsystem.com), has demo videos that can give you a better idea of how it is played using the tiles’ “controller” and workbooks.

*Gala, from page 13*

young Down Syndrome Connection or its earlier version, the Down Syndrome League, where I was the operations manager and fundraiser, as well as chief cook and bottle washer (really). In those days we wore jeans, T-shirts, and buttons announcing who we were and prayed for people to just show up at our fundraisers—which they did. They were in jeans, too.

My name is Janet Richman. I am on the advisory board of the Down Syndrome Connection and was on the Board of Directors of the Connection in the early years. Now I feel like the proud grandparent, an observer of what has grown and blossomed into something beyond my wildest imagination. Before this, I worked with Martha. For many years, it was just the two of us doing what we could to serve the families and their children (no adults then) with Down syndrome. Katherine (aka Kate) Sefton, the genius behind the Step program, taught all the classes by herself until we were able to entice a few volunteers to help her. Martha did what she does now: nurture, encourage, and yes, cry. I did what I could to make sure the doors stayed open so that Martha and Kate could do what they did best. We slowly made ourselves known to the wider community in which we all live, but our progress seemed like baby steps—important ones, but baby steps.

Fast forward to May 5, 2012: hundreds of people, tables of auction goodies, many speakers, live auction items, and a huge (and yes, fancy) dining room filled from wall to wall. All of us were there for one thing: to support an organization that has grown beyond measure, serving so many families and individuals while offering more vital programs. This organization operates smack dab in the middle of the wider community of the Bay Area and is run by a dynamic and absolutely devoted staff of a lot more than three people, plus an incredible Board of Directors dedicated to the mission of the DSCBA. Wow! Now, those were big steps!

I sat at the same table with the Hogans that evening, with whom we have a long friendship (Martha caught my bouquet at our wedding almost 46 years ago!). We just kept looking at each other saying, “Isn’t this incredible?” “Can you believe this?” “This is totally awesome,” I said. And we cried.

## Del Amigo Dolphins' Swim Clinic

**Chris and Jennifer Dodge**

The Del Amigo Dolphins’ Swim Clinic offered to the Down Syndrome Community was a huge success. Coach Janet ran very organized practices that had the children in the pool for the entire hour of each week’s session. Each kid had individual instruction from a coaching staff that was unbelievably supportive, engaged, and helpful. All of the participants in the clinic made clear improvement in swimming skills and comfort in the water. Perhaps most importantly, everyone had a lot of fun!

Our daughter, Ainsley, took an immediate liking to Cayman, her fantastic coach for the program. Ainsley hopes to be back at Del Amigo again next year.

We encourage all parents to take advantage of this fantastic program from the Del Amigo Swim Club if it is offered again.



**Ainsley Dodge and  
her swim coach,  
Cayman Silliman**





## Ready, Set, Action

*Teresa Unnerstall*

“Wash. Wash. Wash.” I hesitated before going into the other room, in fear of what Nick might be doing. Would it be a pair of my shoes in the sink under the faucets running full blast—yet again? To my surprise, I went into the laundry room to witness him taking the dirty clothes off the floor and, one by one, plunking them into the washing machine and, with each one, saying the word “wash”! It hasn’t just been the laundry either. For the past year, he has stepped up in other household chores. Trying to get his brother, Hank, to unload the dishwasher was like trying to pull teeth. But Nick completely enjoys his role that he took over since his brother left for college last fall. Nick is 18 years old and has Down syndrome and autism. He is unable to read but understands and communicates through the use of a picture exchange system and icons he follows on his schedule.



His desire to help out with household chores has really blossomed over the last year. In January I plugged in the vacuum to clean up the fallen needles from the Christmas tree when Nick came in, grabbed the handle, and turned it on. To my surprise, he not only navigated it but held the cord appropriately off to the side and did a nice job running the vacuum across the carpet. I knew he was doing this for his school job at the elder care home but had no idea how precise he was at performing this function.

I have to give all the credit to the staff at his high school. His teacher, Mrs. W, brought in Northern Illinois University (NIU) to do a study of six of her students last year. The abstract was about maintaining vocational skills of individuals with autism and developmental disabilities through video modeling. Video modeling involves a child observing a videotape of a model engaging in a target behavior and subsequently imitating it. It can be used to teach a variety of social, academic, and functional skills both in the school and at the home. Research has shown that video modeling helps to promote independent work-related behaviors and to decrease the reliance on staff. Video-based supports often result in fostering independence and generalization of job-related skills. This means there is less reliance on job coaches and co-workers, all of whom are critical for sustaining competitive employment.

Each video is like a script, breaking down the tasks that need to be performed. These short videos are narrated in the background with simple verbal prompts. Nick watched them every day for two weeks and then each time before he was to perform a particular task. In the case of the NIU study, the videos modeled loading the dishwasher and the washing machine. What I noticed immediately is that Nick enjoyed watching them over and over again. They are much more interesting to him than looking at a task strip. Task strips have simple icons showing step by step the progression of the target behavior. Since using the videotapes I have noticed a significant increase in Nick’s initiative and accuracy in helping out around the house. He can also perform these tasks without any visual prompts (i.e. task strips) and therefore is less prompt-dependent when doing his jobs.

While the jobs are pretty basic, for Nick they mark a milestone. His goals are no longer academic in nature; for the most part, they are all functional. Functional goals are non-academic and are generally understood to refer to skills used in the context of routine activities and daily living. Anything he can do independently gives him not only a better chance to work upon graduation but also a placement into a group home someday. Right now, he also has many other jobs at school including shredding, washing windows, loading the dishwasher, recycling, and washing clothes for the PE department. I have been very pleased with the success of using video modeling and plan to expand this to home tasks. I think the first one we’ll make will be lifting the toilet seat, because the “lift the toilet seat” icon isn’t doing the trick!

## Awesome!

Cathleen Small shared this fun picture with the wish that every baby with Down syndrome gets a shirt like this.



Awesome Sam Small

## Captured Moments

Brothers Quinn and Remy walking in the rain



Nico relaxing after a day of fun in the sun



Creative Audrey designs a masterpiece



# Augmentative Alternative Communication

Kati Skulski, MS, CCC-SLP

## What is AAC?

AAC stands for Augmentative Alternative Communication and has systems and strategies to assist an individual in communicating to their maximum potential. AAC assists the person with all aspects of communication, including production and comprehension. AAC includes aided (picture communication symbols, drawings, speech generating devices, objects, etc.) and unaided (ex. gestures, sign language) methods of communication.

## What is a SGD?

Speech generating devices (SGDs), also known as voice output communication aids, are electronic augmentative and alternative communication (AAC) systems used to supplement or replace speech or writing for individuals with severe speech impairments, enabling them to verbally communicate their needs. A SGD is durable medical equipment and considered medically necessary for AAC users to communicate their medical needs and concerns.

Some insurance plans will cover the funding for a SGD.

## When is AAC needed?

AAC is needed when a person demonstrates an expressive-receptive gap. This means they are able to understand more than they are able to express. For example, a child is able to understand the direction to "Go get your shoes," but when they look for their shoes and cannot locate them, they are unable to ask "Where are my shoes?" This often results in frustration and communication breakdowns. The goal of implementing AAC is to bring a person's expressive language skills to the same level as their receptive language skills. Many speech disorders cause an expressive-receptive gap. Apraxia of Speech and articulation impairments are the most common disorders that impact the speech of individuals with Down syndrome.

## What speech generating devices are out there?

There are hundreds of SGDs available on the market. They are classified into low-, light-,

and high-tech categories. Low-tech SGDs do not run from a power source and are typically communication boards. Light-tech SGDs are battery operated and have one (static) display for vocabulary. Systems typically requiring an electronic power source have a dynamic (changing) display. Depending on the user's needs, a SGD may have symbols, letters, photographs, or words for the person to create their message.

## How do I know which SGD is right?

A Speech Language Pathologist (SLP) who specializes in AAC provides an AAC evaluation. The SLP evaluates the speech, expressive language, receptive language, and access abilities of the client. A communication needs assessment is completed, which evaluates the communication partners, environments, strengths, areas of need, and more. Based on the findings of the evaluation, two to four SGDs are chosen for the individual to try. After trying the devices, the user, family, and SLP determine the best device.

## Will a SGD cause my child to stop speaking?

No. This is a common myth of AAC. In fact, research (Light & Drager, 2010) has proven that the use of AAC does not prohibit speech development but encourages speech by providing natural models.

## What about the iPad?

The iPad with communication applications is a very exciting and ever-expanding addition to the AAC world. Everyone can benefit from an iPad in one way or another. For some people it is a low-cost



Joseph McGrath uses an iPad with the TouchChat application

alternative to expensive, traditional SGDs. However, when considering an iPad with communication applications for a SGD, it is essential that a formal AAC evaluation occur and various SGDs are tried to ensure the iPad is the best fit.

## How can the Connection help?

The Down Syndrome Connection of the Bay Area has been incredibly fortunate to receive a grant from the California Communications Access Foundation. This grant has enabled the Connection to build an AAC lending library, hire an AAC Specialist, and provide workshops and training in AAC. We look forward to helping you learn more about AAC if you think it may help you or someone you love.

*Kati Skulski, MS CCC-SLP is a speech language pathologist specializing in AAC. Kati provides assessments, interventions, and consultations for individuals ranging from infants to adults in the home and educational settings. She works with a wide range of disabilities, communication systems, and strategies.*

*To see how TouchChat works go to the YouTube link: <http://www.youtube.com/watch?v=yfDYHq65NrU> for a 12 minute overview, or come into the Connection to try it out.*

## Thank You Wells Fargo Foundation!

*We are truly grateful for the Wells Fargo Foundation's continued support of our mission and the community we serve.*



**Bob Ceglie, Regional President - Mt. Diablo Market, and Mark Flower, Senior Vice President – East Bay Regional Director, presented a check for \$10,000 to DSCBA staff, board members, and the VandenBerghe family in April. This is the second year Wells Fargo has committed to funding DSCBA Step classes.**



### Baby Steps

Martha Hogan

This June, Baby Steps had a wonderful speaker, Eufrocina, from the Learning Fountain in San Ramon. Eufrocina is an occupational therapist and spoke to us



Caleb Sugianto

about our sensory systems and how they work. It was extremely informative and taught us a great deal about how we are *all* impacted by our sensory systems, not just our kids with Down syndrome. Everyone learned a great deal.

At the end of the session, Eufrocina worked with each child and was able to address individual issues that parents brought up about their children. At the end of the day, both parents and children really had a good time learning and playing together.

A big thank you to Eufrocina—we look forward to having her come again.

The Baby Steps class with Eufrocina



Oliver Pongkhasing



Eufrocina, Ian Randick, and Mari Pongkhasming

### Small Steps

Laura Briggs

Keeping with our winter theme book *Snowmen at Night*, Small Steps made these adorable and very delicious snowman pancakes.



We always enjoy cooking day. We love to measure and stir—but most of all we love to eat, at least most of us do. (Sorry Cole!)



### Step Out

Harold Burns

This semester Step Out explored love and relationships. We discussed how our lives can generally be seen as having four kinds of love: family, friends, romantic, and self-love. We talked about the many complexities that love can entail, for example how to balance loving yourself while also loving someone else. We also took cameras into the community to document the loving relationships that surround each one of us. The result was a beautiful series of collages representing the constellation of loving relationships that surrounds each student.



Putting together and enjoying our collages

### Steppin' Up Steps Out

Laura Briggs

The Steppin' Up class took a walking field trip to the newly expanded local toy store, Games Unlimited. We had to check out all the great things they have—and, boy, did they ever! We all found something that we just had to have. Daniel and Sean liked a Star Wars book, Clio teased us all with the super-cool "claw," and Nicole thought the claw was really neat too.

On another field trip we went to the bowling alley, and a great time was had by all.

Steppin' Up really enjoys "stepping out" into the community and looks forward to more trips in the fall.



Above, Anthony Godinez



At left, Daniel Sodestrom

### Step In

Tamara Reed



The Danville Step In class poses with Joyce Castro from the San Ramon Valley Fire District. The class reviewed house safety with the fire department's three dimensional "Hazard House."



Blair Hogan and the San Ramon Valley Fire Prevention's vehicle.

### SF Step: Farewell Chloe

Harold Burns

This summer, Chloe Pollock, a beloved member of SF Step, is taking a big step: out of her mother's home and into a great supported-living community in Marin. Chloe is very excited to make new friends and expand her

independence. Her friends at SF Step are sad to see her go but excited for her new opportunities. The class planned and organized a wonderful farewell party with healthy food to honor her transition.



SF Step Class dances to their favorite songs



Robert Humphreys and Matt Hillman



Chloe Pollock shows off her Special Olympic medals



Olivia Byers-Straus and Jackson Soderquist



Chloe Pollock and Emma Yungert

### Eli Receives an Award

Jennifer Cooper

Eli Cooper

Eli was one of many impressive high school students honored by Berkeley Mayor Tom Bates for various impressive endeavors and achievements. Eli received an Excellence in Community Service award for his work in educating students about ability awareness and the Spread the Word to End the Word campaign. Eli's family and friends are all very proud.



### Step In Enjoys Movie Night

Marianne Iversen

Movie night at the Connection was a big success for the Step In group. We ordered pizza, and Stacey made popcorn. Several people brought movies to play. Blair Hogan's movie, School of Rock, was chosen for the first feature, and it did rock! Athena's classic movie, Lady and The Tramp, completed our double feature. Brandon Herbert, whom we haven't seen in a while, joined us. It was great seeing him.

We were able to have this wonderful night because of the hard work Step In did fundraising with a pasta dinner and a car wash in October. Thank you to all the parents for coming in and supporting us. Thank you to the Step In Steppers for all your hard work making, serving, and cleaning up after dinner, as well as washing all those cars. We look forward to many more movie nights at the Connection.

### Fun and Learning Continues in Next Step

Marianne Iversen

What a great time the Next Step class has been having this spring. In February we hosted a Valentine's Day party for our moms. Each participant stood up in front of the classroom and told their mom why they loved them and presented her with a rose and a gift. We also completed several art projects throughout the sessions, most of which focused on utilizing our fine motor skills. One of our favorite projects



was the tile art where each student painted tiles with an ink-dye process. They turned out so beautifully that we decided to frame a mirror with them, which we then auctioned off at our Gala. We had a great field trip to Whole Foods where we received a tour of the supermarket and learned lots of interesting facts about fruits, vegetables, cheeses, and, of course, their wonderful bakery items. When we asked everyone what was their favorite part of the field trip, the most common answer was the "free samples."



Top left, T. J. Crawford painting tile  
Top right, Erika and Emma Tippet  
At left, Next Step visits Whole Foods



Above, getting ready for the movie to begin

Right, Stacey Elliott, Katrina Taylor, and K. Leigh Alfrey—looking pretty comfy for movie night





## Deven's Journey in Kung Fu

Vesta Mistry

When Deven was about four or five, our kung fu master, Master Tomizaki, asked if I planned to put Deven in kung fu. I shook my head and thought, no way. He wouldn't be able to keep up with the other students or the pace of the training itself. He wouldn't be able to pay attention and listen to the instructions given to him. Would he even be able to process what was asked of him as quickly as he needed to? I wasn't sure. It made me sad and a little angry because my heart longed for him to do activities like "all the other kids," but my head kept saying, he can't do it. Even when Master Tomizaki kept telling me Deven could do it and he'd be better than even I hoped he'd be, I still didn't believe it—and I trust our master implicitly. I was fearful of Deven failing. I didn't have the faith in Deven that Master Tomizaki seemed to have, so I let it go. Then one day, a couple of months later, I took Deven with me to watch a belt graduation. He sat on my lap and watched the entire two-hour graduation. He didn't lose interest or seem bored at all. When we got home, he picked up a pillow from our couch and promptly instructed (demanded, is more like it) his little brother to get into his fighting stance and kick the "pads." He even counted kicks—in *Chinese*. I was amazed that he not only watched, but he learned in those two hours! I was also very excited that kung fu was actually a possibility for Deven. That was three years ago.

He started training privately with Master Tomizaki. Some days Deven could only focus for about 10 to 15 minutes, but other days he would train the entire 45 minutes.

I watched with uncertainty and amusement: Deven was uncoordinated, off balance, silly, and would sometimes do his own thing. Yet through it all, Master Tomizaki stayed patient and encouraged both of us. Deven kept up his training and eventually moved into regular classes with all of the other Grasshoppers. His growth, from day one to today, has been incredible; he inspires me every day. He is now in the beginner Juniors class and is keeping up with peers his own age. This has been an awesome journey for all of us: from the initial private lessons, through a white belt, a gold belt, and an orange belt, to the green belt he proudly wears today. At his last belt promotion, where he was promoted to a Green Grasshopper, he graduated with a typical mix of Grasshoppers, Juniors, and adults. He kept pace and did everything he was asked to do, including two-hand forms and self-defense. It was very cool!

Deven continues to train hard and can count to about 15 in Chinese. And check out his side kick! Master Tomizaki and all of the amazing instructors at Tomizaki's Champions expect nothing less of Deven than they do of the other students and they don't give him any special treatment or instructions. They

expect Deven to focus, pay attention, and follow along with the flow of the class. The other students treat him with respect, as well, and are all very supportive, encouraging, and kind. He gets treated like everyone else, which is all any parent can hope for—especially a parent of a child with special needs.

At the end of the graduation that Deven participated in, Master Tomizaki spoke about how proud he is of all of his students but pointed out Deven's growth, progress, and dedication to

his training. His words really touched my husband and me. It is evident that Master Tomizaki, the amazing instructors, and the students have unwavering faith and confidence in Deven. Even though Deven has Down syndrome, it doesn't stop him from learning, growing, giving his all, and doing his best. It doesn't stop him from doing anything at all. He really is just like "all the other kids." And the best part? It seems to be me who needs a reminder of that from time to time—everyone else already knows it.

At right, Deven kicks hard

Below left, Deven looks good in green!

Below right, Deven (front row, center) with his green belt graduating class



Deven's side kick

Deven and Master Tomizaki

Deven and his brother, Ryan



## Pinole and Benicia Step Welcome a New Pal

Brian Fruchey

My name is Brian Fruchey. I am a remote volunteer, via Skype from Ohio, for the Pinole and Benicia Step groups. I have cerebral palsy, and I know what it's



like to live with a disability. I find it very rewarding to share my experience and to make a difference in other people's lives.

The first week as a remote volunteer I was a little apprehensive about how they would respond, not only to someone new, but to someone who was not physically in the room. I was pleasantly surprised at how quickly I was able to build a rapport with the group. After five minutes, I felt like I'd known them for a lifetime. It was fun getting to know everyone, and I look forward to working with the Down Syndrome Connection in the future.

## Pinole Step

Tamara Reed

The group learns to handle snakes!



Clockwise from top left: Angel Love, Michael Mariuzza, Jared Wong and Angel Love

## Benicia Step: Movie Review

Lisa Silva

My friends and I went to see "MIB (Men in Black III)." It was a really good movie! I liked the part where Will Smith was bowling with the alien's head, but Martin liked the part where the aliens had a party. The movie was cool!



## Futures Explored Program

Pat Elliott

Futures Explored is a wonderful program for developmentally disabled adults. It offers work and volunteer opportunities, fun classes, field trips, and even overnight trips. Stacey has been attending Futures since 2008, and it has been a very important part of her life. She has been able to explore many different interests and activities, and she has loved it.

The Drama Class at Futures Explored is one of the most popular classes, highlighted by the annual drama performance. Students learn all aspects of producing a well-

organized and creative production. The audience response to the actors is always heartwarming as parents, family, and friends see the actors take center stage. The students display confidence and a real sense of accomplishment when they perform. Stacey has been a part of the drama class for four years, and it has always been her favorite class. This year one of the numbers she participated in was "Rainbow Connection" for which she performed in sign language—and did a fantastic job!



Above, K. Leigh Alfrey, Katrina Taylor, and Stacey Elliott

Left, DSCBA Step teacher Tamara Reed attended the performance.

**No one SPARKLES like these athletes!**

The Cheergyms.com Special Needs program was the first of its kind on the West Coast and we are now proud to be entering our 8th year of All Star Cheer!

If you know of a person with any Special Needs at all, this is the place for them to work hard, be part of a team and reach their true athletic potential! SPARKLE!

Team practices begin in August. Summer Camps and Clinics are also available.

Call now for more information or Email Jodi Kandl [jodi@cheergyms.com](mailto:jodi@cheergyms.com)

Cheergyms.com Inc. • 2060 Commerce Ave., • Concord, CA • 94520 • 925-685-3910



**Special Olympians**

Marianne Iversen

On May 1, Special Olympics Northern California hosted the Bay Area Schools Competition at Acalanes High School. This was a fun-filled day with track and field events such as the 50- and 100-meter dash, long jump, javelin, and softball throw. Each activity allowed the participants to show off their athletic talents and offered an opportunity to build and expand their friendships with other athletes and Acalanes student volunteers. It was a day full of pride for the athletes, volunteers, and spectators alike.



Patrick Harkins



Tatiana Casadont



Adam Ferguson



Vikram Ramiya



T.J. Crawford

**2012 Bay Area Step Up for Down Syndrome Walk & Picnic**

*Benefitting the Down Syndrome Connection of the Bay Area*

In 2012 we are joining with other Down syndrome affiliate groups across the country to re-brand our annual walk. The Bay Area Step Up For Down Syndrome Walk is our effort to include Down syndrome in the event name, along with creating a positive call to action for the entire community. It is the same event in every other way.



**GATHER UP  
A TEAM  
AND WALK  
A MILE FOR  
DOWN  
SYNDROME!  
HELP US  
RAISE  
\$150K**

Little Hills Ranch, San Ramon  
Sunday, October 7, 2012  
10:30 – 11:30 a.m. registration  
12:00 p.m. SHARP – walk begins



**\$30.00 per person - Children 5 & under and people with Down syndrome are always free. Registration includes: A Step Up for DS T-shirt, BBQ lunch, and many activities such as swimming, fishing, rock climbing wall, bouncy house, airbrush tattooing, and more.**

**Start Fundraising and Register NOW:  
[www.firstgiving.com/dscba](http://www.firstgiving.com/dscba)**

**PLEASE REGISTER BEFORE SEPTEMBER 1ST—AFTER SEPTEMBER 1ST THE REGISTRATION PRICE WILL INCREASE AND LUNCH AND SHIRTS CANNOT BE GUARANTEED. MORE THAN 1,100 PEOPLE CAME TO THE WALK IN 2011 AND, OF THOSE, ONLY 600 PEOPLE REGISTERED ONLINE. PLEASE HELP US COORDINATE A GREAT EVENT BY REGISTERING ONLINE EARLY SO WE CAN PREPARE TO MAKE IT A GREAT DAY!**

*While registering, please create a personal fundraising webpage. Email it to your friends, family, and co-workers asking them to sponsor your walker or your team.*

**NEW in 2012:** If you cannot attend the walk, please register as a “Virtual Walker” for free and send a Web page to everyone in support of someone you love with your personal story. By registering as a Virtual Walker, friends and family—no matter where they live—can create a page in honor of your walker or team supporting the DSCBA.

**The Step Up for Down Syndrome Walk is the DSCBA’s largest source of funding. Please help us meet our goal of \$150K. Thanks for your support.**

☆ ☆ ☆ ☆ ☆ ☆ ☆ **2012 FALL SCHEDULE** ☆ ☆ ☆ ☆ ☆ ☆ ☆

### Danville Location Classes

#### MUSIC THERAPY

Therapist - Nicole Patton, MA,  
MT-BC

1<sup>st</sup> Saturday of every month  
Aug. 4, Sep. 8, Oct. 6,  
Nov. 3 and Dec. 1

Ages 0-4 years:

10:00 a.m.-11:30 a.m.

Ages 5-10: 12:15-1:45 p.m.

#### BABY STEPS

Facilitator - Martha Hogan

3<sup>rd</sup> Wednesday every month  
(with some exceptions)

Aug. 15, Sep. 19, Oct. 17

No Nov. class, Dec. 5

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 - Sep. 17, 24; Oct. 1, 8,  
15, 22

Session 2 - Nov. 5, 26

Dec. 3, 10, 17

#### STEPPIN' UP

Teacher - Laura Briggs

Ages 8-13 years

Wednesday - 3:30-5:00 p.m.

Session 1 - Sep. 19, 26

Oct. 3, 10, 17, 24

Session 2 - Nov. 7, 14, 28

Dec. 5, 12, 19

#### NEXT STEP

Teacher - Marianne Iversen

Ages 13-19 years

Tuesday - 4:00-5:30 p.m.

Session 1 - Sep. 18, 25

Oct. 2, 9, 16, 23

Session 2 - Nov. 6, 13, 27

Dec. 4, 11, 18

#### STEP IN

Teachers: Virginia Bonham

Tamara Reed

Ages 19 years and up

Thursday - 4:00-5:30 p.m.

Session 1 - Sep. 20, 27

Oct. 4, 11, 18, 25

Session 2 - Nov. 8, 15, 29

Dec. 6, 13, 20

### Bay Area Adult Classes

#### SF STEP

Teachers: Harold Burns  
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 - Sep. 18, 25

Oct. 2, 9, 16, 23

Session 2 - Nov. 6, 13, 27

Dec. 4, 11, 18

#### STEP OUT

Teachers: Harold Burns  
Virginia Bonham

Location: Interplay

(Body Wisdom Inc)

2273 Telegraph Rd., **Oakland**

Wednesday - 3:45-5:15 p.m.

Session 1 - Sep. 19, 26

Oct. 3, 10, 17, 24

Session 2 - Nov. 7, 14, 28

Dec. 5, 12, 19

#### BENICIA STEP

Teacher: Tamara Reed

Location: PACE Benicia, 425-E

Military East, **Benicia**

Wednesday - 4:00-5:30 p.m.

Session 1 - Sep. 19, 26

Oct. 3, 10, 17, 24

Session 2 - Nov. 7, 14, 28

Dec. 5, 12, 19

#### PINOLE STEP

Teacher: Tamara Reed

Location: Kaiser Medical Facility  
Conference Room 1A/B

1301 Pinole Valley Rd., **Pinole**

Friday - 3:30-5:00 p.m.

Session 1 - Sep. 21, 28

Oct. 5, 12, 19, 26

Session 2 - Nov. 9, 16, 30

Dec. 7, 14, 21

### Summer Sibling Support

**Don't miss out! Four summer sibling support sessions - full of fun & education with Terese Ghilarducci, MFT**

Location: DSCBA, 101 J Town & Country Dr., Danville

- Saturday, August 4 10:00-11:30 a.m.
- Saturday, August 11 10:00-11:30 a.m.
- Saturday, August 18 10:00-11:30 a.m.
- Saturday, August 25 10:00-11:30 a.m.

Fee: \$15 per session, per participant. Welcoming ages 7 years and older. Note: If less than four participants sign up the group will be cancelled. Individual sessions can be arranged with Terese.

If you have questions or to RSVP, please email Terese at [terese.mariieg@comcast.net](mailto:terese.mariieg@comcast.net).

### Support Group Schedule Summer/Fall 2012

#### PARENT SUPPORT GROUP

Facilitator: Martha Hogan,  
Location - DSCBA, Danville

Tuesdays (usually the 4<sup>th</sup>

Tuesday of each month)

7:00-9:00 p.m.

Jul. 24, No Aug. mtg., Sep. 25,

Oct. 23, No Nov. mtg., Dec. 4

#### GRANDPARENT SUPPORT GROUP

Facilitator: Martha Hogan,

Location - DSCBA, Danville

Wednesdays (usually the 4<sup>th</sup>

Wednesday of each month)

10:00-11:30 a.m.

Jul. 25, No Aug. mtg., Sep. 26,

Oct. 24, Nov. 28, No Dec. mtg.

#### SUPPORT FOR PARENTS WITH ADULT CHILDREN

Facilitators: Marianne Iversen &  
Tamara Reed

Location - DSCBA, Danville

Thursdays (the 3<sup>rd</sup> Thursday,  
every other month)

7:00-9:00 p.m.

Jul. 19, Sep. 20, Nov. 15

RSVP if interested

#### EDUCATIONAL SUPPORT GROUP

**(IEP/SDC/Inclusion)**

Facilitator: Martha Hogan,

Location - DSCBA, Danville

Wednesdays (3<sup>rd</sup> Wednesday of  
each month)

7:15-9:00 p.m.

Jul. 18, No Aug. mtg., Sep. 19,

Oct. 17, No Nov. mtg., Dec. 19

#### SIBLING SUPPORT

Facilitator: Terese Ghilarducci,

Location - DSCBA, Danville

Saturdays (All Saturdays in

August)

10:00-11:30 a.m.

Aug. 4, 11, 18, 25

RSVP if interested

#### FATHER SUPPORT GROUP

Facilitator: Dr. Rick LaBelle

If you are interested in learning  
more about this group, please  
call the Connection.

## SOCIALLY CONNECTED!

Check us out on  
Facebook at [WWW.FACEBOOK.COM/DSCBA](http://WWW.FACEBOOK.COM/DSCBA)

OVER 375 FANS SO FAR

WHY DON'T YOU BECOME ONE TOO?



GET UPDATES FROM THE CONNECTION AND LEARN ABOUT  
EVENTS, FANS CAN POST TEXT, PHOTOS AND VIDEO TO  
DSCBA'S PAGE.



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

## Foundations, Family Funds, and Service Organizations

Maurice Amado Foundation  
Barr Family Foundation  
Ray Benton Family Fund  
California Communications Access Foundation  
The Columbus Foundation  
Diablo Country Club Foundation  
Carl Gellert and Celia Berta Gellert Foundation  
Heffernan Group Foundation  
Jam Handy Character Building Foundation  
Kiwans Club of Pleasanton  
Kiwans 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  
Lowell Berry Foundation  
M Squared Consulting  
Peter Musto Charitable Trust  
NAILBA Charitable Foundation  
Noll Foundation  
Quest Foundation  
San Ramon Rotary  
Wayne and Gladys Valley Foundation  
Wells Fargo Foundation

## Agilent Technologies Foundation

Simon Baldia Nunez

## AT&T Employee Giving Campaign

David Kimble	Raymond Rhodes
Joanne Leach	Kim Wolken
	Krista Veri

## Car Donation Services

Mike Cooley	Steve Grimes
Patrick Gray	Adam Vaughn

## Chevron Humankind

Paul Casadont	Edward Oda
Mark T. Janke	Scott Truger

## Community Health Charities of CA

Judy L. Hawkins	Janet Holmes
	Edwin Ostrowski

## Gap Employee Matching

Lisa M. Priggs in memory of  
Emma Krumwiede

## Kaiser Community Giving Program

Burt Hasiguchi	Gail Hibson-Lawton
Richard LaBelle	Larry Lawton
	Wanda Haskell

## Microsoft Matching Gifts Program

Howard L. Cooperstein

## PG&E Corporation Campaign for the Community

Mary Galvin	Derek Kent
	Lleny Rios

## Vista Grande and PRIDE Fundraiser

The Huether Family

## Wells Fargo Community Support Campaign

Anonymous

## General Donations

Alessio Carli  
Chatowski Family  
Heather Greenfield  
Helping Hands/Waterman Chiropractic Center  
Janine Herhut  
Shahryar Hussain  
Janet Richman  
Jeanne Riely

## In Honor of the Adult Step Groups

Anonymous

## In Honor of Katie Marie Buckman's Birthday

Erika Walters & EK Buckman

## In Honor of Tatiana Casadont

Elena Orta Martin

## In Honor of Mr. Kellin Cooper for his Services to the Legal Community

Michael Urbanos and the  
Rosann Fischer Family

## In Honor of Silke Linke

Daniela Relaford

## In Honor of Heather Peterson

Chery Damgen

## In Honor of Heather and Karen Peterson

Lynn Bloch

## In Honor of Ian Andrew Randick

Robert and Marlys Randick

## On Behalf of Their Wedding Guests

Kate VandenBerghe and  
Jason Roysdon

## In Honor of Mason Zolnier

James and Kathy Zolnier

## In Honor of the Newest Addition: Major Alexander Zolnier

Victor and Kathy VandenBerghe

## In Memory of Gordon Ball

Martha and Kevin Hogan

## In Memory of Mario Barillas

Michael and Karen Zolnier

## In Memory of Dorothy "Dot" Wishart Lorenzetti

Michael and Karen Zolnier

## In Memory of Don Maxwell

Martha and Kevin Hogan  
Velma Magnani

## In Memory of Bob Muenther

Martha and Kevin Hogan

## 2012 Gala Supporters

Tom Vacar, Master of Ceremonies  
Dennis McCormac, Auctioneer  
Kshama Perera, Event Planner  
Lisa Upton, Photographer  
Marty and Veronica Barillas  
CCAF Board of Directors  
Chevron – Jeff Swindell and Marian Catedral  
Maria Dereschuk Family  
Diablo Country Club  
The DSCBA Board of Directors  
The DSCBA Staff  
Farmers Insurance – Bob Herzog  
The Gala Committee  
John and Judi Garcia  
Janelle Lembeck  
Mike Mendez  
John and Katherine Portoni  
Public Eye  
The VandenBerghe Family  
Wells Fargo – Ed McElroy  
Avenue Wine Company  
*To all of the Gala donors, sponsors, and volunteers, we are truly grateful!*

## 2012 Annual Conference Volunteers

Laura Redmond  
Circle K-University of California Berkeley  
Kamp Kesem Volunteers  
Nicole Patton, Music Therapist  
Terese Ghilarducci

## 2012 Gala Volunteers

Chris Anthony	Conner Anthony
Mike Arwine	Noelle Austin
Jenn Bornstein	Tami Castelluccio
Maureen Cummings	
Carin Elam	Sophia Friedler
Dawn Garlieb	Terese Ghilarducci
Traci Golis	Stacy Kadesh
Marcela Kamp	Jo Kelley
Debbie Kratky	Toni Liebowitz
Vesta Mistry	Niro Perera
Angie Rettig	Tina Risse
Lauren Rose	Jeset Sidore
Laura Redmond & UC Berkeley Friends	
Camp Kesem Volunteers	
National Charity League-Diablo Valley Chapter members:	
Jane & Linda Fountain	
Anna, Elizabeth & Eve Vojvoda	
Megan & Michele Wastal	

## Dedicated Classroom Volunteers

K. Leigh Alfrey	Lauren Bruno
Tawny Burns	Jensine Chen
Andreas Dereschuk	
Matthew Duckett	
Sean Duckett	Dawn Handley
Camille Hunt	Mira Khawam
Macee LeMoine	Alexis Liebowitz
Elyse Perry	Laura Redmond
Paula Ridley	Lynn Sanford
	Logan Silliman

## DSCBA Programs Can Only Continue with Your Help! 43% of our funding comes from our fundraising events

**CASH DONATIONS** Send a check to: Down Syndrome Connection of the Bay Area, 101-J Town and Country Drive, Danville, CA 94526. Phone: 925-362-8660

**DONATE WITH PAYJUNCTION** The DSCBA is a member of PayJunction a free service that allows you to purchase or donate using your credit card on a secure Web site. PayJunction deposits your donation directly to our account. Visa and MasterCard are accepted at [www.dsconnection.org](http://www.dsconnection.org).

**DONATE AN AUCTION ITEM** This is a great opportunity to showcase your business products and services or to give a great tax-deductible item to be auctioned at one of our events. Some past items that are popular are wine packages, vacation homes, sports memorabilia, fine art, jewelry, spa packages etc.

**SPONSOR AN EVENT** Sponsor an event at a level that works for you. Publicize, advertise and show off your company logo while giving to a worthwhile cause. Have a booth and speak at our event.

**HOLD A FUNDRAISER TO BENEFIT THE CONNECTION** We are looking for community service organizations or businesses to hold a benefit in our name. One way to do this is to have a charity golf tournament, auction/dinner or crab feed to name a few. Have ideas? Please call the Connection.

**VOLUNTEER** Do your community service with us! Volunteer your time and work at an event, spend time in one of our classes, come help out with newsletter mailings and other projects. Call us for more information.

**CORPORATE GIVING AND MATCHING GIFT PROGRAMS** Sign up for your corporate giving program at work, which automatically can be taken out of your paycheck. Some companies even have matching programs, which doubles your giving ability.

**ATTEND A FUNDRAISING EVENT** We would love to see you at our fundraisers such as our Gala and walk. Your participation and support make a huge difference and our events are a lot of fun!

**DONATE YOUR CAR** Call us at the Connection at 925-362-8660 to find out how you can donate your car and in turn give back to the Connection. You may also call (877)700-GIVE or visit [www.carsforcharities.com/DSC.htm](http://www.carsforcharities.com/DSC.htm)

**SIGN UP FOR THE ESCRIP PROGRAM** eScrip is an easy way to give back to the Connection! Just register your grocery, debit or credit cards at merchants such as Safeway, Macys, Nordstrom or eBay for example. A portion of your purchase will be donated to the Connection. Visit [www.escrip.com](http://www.escrip.com) to get started. ID#4843658. TAX ID# 91-1904304

## How Can You Help?

★ ★ ★ ★ ★ ★ ★ ★ ★ ★ **UPCOMING EVENTS** ★ ★ ★ ★ ★ ★ ★ ★ ★ ★

★ **S**ibling Support – August 4, 11, 18, 25 (see page 22)

**S**tep up for DS – Sunday, October 7 (see page 21)

**H**abitot for DSCBA Families – FREE FUN DAY  
Wednesday, August 8 (see below)

**S**ave the Date – 2012 Holiday Party  
Sunday, December 2

**E**ducator Training – Down Syndrome 101  
Wednesday, September 12, 2:30–6 p.m. (dinner served)

**S**ave the Date – DSCBA Empowerment Conference and  
Annual Meeting – Saturday, March 9, 2013 (see page 4)



**Making the Connection**

Down Syndrome Connection of the Bay Area  
Phone 925-362-8660 • Fax 925-362-8663  
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**FREE Habitot visit for your family!**

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

**Special Times for Special Families**

**WHAT:** A special opportunity for families with children ages 0-7 to have exclusive after-hours use of Habitot Children's Museum. Come and enjoy hands-on exhibits, art activities, socialization, and family bonding time!

Please bring a change of clothing for your child. *Light snacks will be provided.*

**WHEN:** Wednesday, August 8 • 1:00-3:00p.m.

**WHERE:** Habitot Children's Museum  
2065 Kittredge Street  
Downtown Berkeley  
*one block from Downtown Berkeley BART*

**RSVP:** By August 3  
Kathy at DSCBA 925-362-8660  
or [Kathy@dsconnection.org](mailto:Kathy@dsconnection.org)

