This was yet another year of record-breaking temperatures at the San Ramon Valley Kiwanis Danville July 4th Parade. It wasn’t only the temperature that was hot; leading the parade as the Grand Marshal was our very own Martha Hogan! Martha was chosen by the Kiwanis Club due to her outstanding leadership and commitment to the community. The parade’s theme this year was People Helping People, and that is what Martha intended and did for the DSCBA when she started it in 1998. In her current role as Director of Parent Support, she still gives hope and

Continued on page 3
A Note from Nancy

Nancy LaBelle
Executive Director

Happy summer, everyone! It’s been a busy one at the Connection as we explore new programs and welcome many new families. Once again, the community has been very good to us. We are fortunate to have donors who believe in our mission and truly understand the importance and impact of what we do. They also understand our need for growth, which gives us hope for future programs and expansion.

We are off to a solid financial year thanks to many foundations, service groups, general donors and our members who believe in our mission. To date we have received a total of $215,000, which is approximately one third of our annual budgetary goal. We are humble by the generosity of the community and honored to give thanks on our gratitude list on page 19.

The Bay Area Step Up for Down Syndrome Walk is now open for registration. This event and the Gala in spring make up almost 40% of our budget. We are hoping that everyone who created a fundraising page last year will create one again—over $140,000 in donations were collected last year. We are counting on those of you who have not created a page to help us this year. It is the only way we keep our doors open. Visit www.dsconnection.org/stepup today.

As we move into the second half of the year, my focus remains on learning more about the support that specific schools provide for children with Down syndrome to communicate their basic needs and to participate to their full potential in class with their typically developing peers. As most of you know, communication is a passion of mine. I believe it is also the foundation for independence and can lead to well-paying jobs as young adults leave school to give back to the community.

Our summer pilot program to understand communication readiness and what kindergartners and first graders need to be successful has been a huge success in the three weeks of an eight-week program, as you will see on page 14. My hope is that our program transition plan that follows the children into school this fall will be welcomed and utilized in IEP goal-setting planning and that the children’s education team reaches out to us when they need help. Parents must continue to remind your child’s school teams that we are here for them and that we know your kids and can help. We have free training, consultation, in-classroom help, an AAC lending library, and support and curriculum that can be borrowed. Our Down Syndrome Educational Alliance (DSEA) has opened doors we never thought would open. In the fall, we will once again start our DSEA training programs, ability awareness presentations, and consultations for school administrators and their teams who will take advantage of this amazing opportunity.

I hope you enjoy the rest of your summer and that this newsletter makes you proud of someone you love, gives you a smile, and helps you to understand the magnitude of what we can all accomplish together.

2013 Board of Directors
Terese Ghilarducci, President teresemarieq@comcast.net
Mike Zolnier, President Elect mike@vdprop.com
Judith Clark, Secretary Judith.delements@gmail.com
Paul Crawford Treasurers paulcrawford311@gmail.com
Marty Barillas marty.barillas@chevron.com
Mary Brody marylouis@chevron.com

Board Meetings in 2013
101 J Town & Country Drive Danville, 6:45–8:15 p.m.
The Board meets on the 3rd Tuesday of the month: Aug. 20, Sep. 17, Oct. 15, Nov. 19, no Dec. meeting. To attend or bring a guest please call the Board President, Terese Ghilarducci at 925-872-5858.

Welcome to our two new board members David Fazio and Marty Barillas
David is an advocate in the disability community and the CEO of his own company called Helix Opportunity, which facilitates inclusion in the business world. Marty comes to us from Chevron and is the proud father of son Nico. Marty was introduced at our Empowerment Conference and presented a donation from Chevron. Our long standing board members continue to work hard with lots of dedication: Paul Crawford, Treasurer, Judith Clark, Secretary, Mary Brody, Andreas Dereschuk, Tammy Garcia, Tim Hogan, Karen Zolnier, Mike Zolnier, President Elect, and Terese Ghilarducci, President.

2013 Advisory Board
Natalie Hale
Reading & Handwriting Consultant info@specialreads.com
Tim Lane, Attorney at Law jlaneesq@aol.com
Nicole Patton, Music Therapist mrsmusic@mac.com
Maura Perkins, Past Board President mperkins@mkni.com
Amien Punjani Business Owner/Consultant apunjani@ameritconsulting.com
Janet Richman janetrichman@comcast.net
Katherine Sefton Developmental Therapist kathleen50@yahoo.com
Julie Sodestrom, Past Board President jsodestrom@comcast.net
Tracy Trotter, MD, Pediatrician ttrotter@srvpc.com

DSCBA Staff
Peggy Alreck-Anthony Office Manager peggy@dsconnection.org
Virginia Bonham, Teacher vance1959@att.net
Laura Briggs, Teacher lbriggs21@comcast.net
Harold Burns, Teacher haroldburns3@gmail.com
Jennifer Cooper, Co-Director Parent Support & Education Coopers4@pacbell.net
Nancy Ferguson DSEA Program Manager nferguson@dsconnection.org
Kathy Harkins Event Administrator kathy@dsconnection.org
Martha Hogan, Director of Parent Advocacy and Support marthogan@sbcglobal.net

Marianne Iversen
Director of Programs marianne@dsconnection.org
Nancy LaBelle, Executive Director nancy@dsconnection.org
Christina Lewis, Teacher dottymoppet@yahoo.com
Tamara Reed, Teacher tamarawreed@yahoo.com

DSGBA Consultants
Karen Baca, Education Technology Specialist karenbaca@sbcglobal.net
Tempra Board, Grant Manager tempra@tempra.com
Kathy Miles, Reading Teacher kmmiles@pacbell.net
Nicole Patton, Music Therapist mrsmusic@mac.com
Heather Peterson, SLP/OPT heather@happykidstherapy.com
Kati Skulski, SLP/AAC Specialist kaskulski@gmail.com

Down Syndrome Connection of the Bay Area
www.dsconnection.org
Phone 925.362.8660
Fax 925.362.8663
101 J Town & Country Drive
Danville, CA 94526

Visit www.dsconnection.org/stepup today.
We celebrated, educated, and played on World Down Syndrome Day, March 21. This is a day where the inclusion and acceptance of people with Down syndrome is celebrated and encouraged across the world.

At the Connection, World Down Syndrome Day was ushered in by the Step In gang with great enthusiasm. They wanted to spread the word that they have pride in who they are and that having Down syndrome is one piece of their make-up; they are also artists, dancers, cooks, athletes, and writers. Step In has been focusing on positive growth personally and what they can do professionally as adults. The class created a banner and had an information table with flyers and other information about Down syndrome. They also shared cheers and treats with the Danville community to show their talents and pride.

Eli and Jennifer Cooper celebrated World Down Syndrome Day by giving ability awareness presentations to over 150 students at a Berkeley middle school. They discussed everything from chromosomes, muscle tone, and Individual Education Plans (IEPs) to Eli’s musical tastes, his drama involvement, and stopping the use of the R-word. The students particularly enjoyed the marshmallow activity: they talked with a marshmallow in their mouth to simulate low muscle tone. They learned that it was work to try to enunciate and that they could usually understand their partner if they focused carefully. By the end of the presentations, the students realized that they had a lot in common with Eli and looked to him as a leader in their community. More importantly, they realized that Down syndrome was not a bad thing—just a different thing.

We also played and celebrated with many families at the opening celebration of the inclusive playground at Athan Downs park in San Ramon. The playground is designed for kids of all abilities to play together. It includes ramps for wheelchairs and those with limited mobility, sand play, interactive panels for tactile play, sensory-stimulating activities, and areas for quiet play. Families from all over the Bay Area came to celebrate in this wonderful playground, as well as to educate the public by fostering integrated and inclusive play within our communities. It was a perfect afternoon of fun in the sun!
On May 4, the 2013 annual Gala for Giving took place and proved, once again, to be a night to remember.

As before, Diablo Country Club was the gracious host for the evening of fine food and wine shared by both friends and families of the Down syndrome community. The women were striking in their dresses, the floral centerpieces were uplifting, but beyond the glitz and glam of the night was a real purpose that called every attendee there.

The Gala is the first of two of the Down Syndrome Connection of the Bay Area’s (DSCBA) annual fundraisers. This event typically makes up 30% of the annual budget, so the success of the evening is incredibly important to the organization.

Nancy LaBelle, Executive Director, was honored for her five years of dedication and for overseeing amazing growth at the DSCBA. Martha Hogan and Mike Zolnier presented Nancy with a gift as the crowd gave her a standing ovation. One of the highlights of...
Continued from page 4

the evening was when DSCBA members Marty and Veronica Barillas graciously shared their warm heartwarming personal journey of romance, love, and their beautiful son Nico. We were very happy to have many families who have amazing adults with Down syndrome come out to party. When the DJ rocked the house, together we danced and celebrated the night until it drew to an end.

Gala attendees learned about important programs such as the Down Syndrome Educational Alliance with Bay Area school districts and the upcoming Communication Readiness Program pilot for children entering kindergarten and first grade. For those families and friends touched directly by Down syndrome, DSCBA programs help people of all ages maximize their potential and give them a voice when they may otherwise not have one. The funds raised at the Gala make that happen.

To that end, we'd like to recognize and thank our Platinum Event Sponsor and friends at Chevron Corp. Chevron has been a strong supporter of the Connection for a number of years, and their sponsorship helped to defray costs of the event. Wells Fargo Foundation is also a supporter of our programs and a VIP Table Sponsor this year, once again. We also want to thank additional VIP Table Sponsors: Herzog Farmers Insurance, Baker Hughes, the Garcia, Dereschuk, and VandenBerghe-Zolnier families—and everyone else who attended the Gala.

We are grateful for all of our auction donors and for our wine sponsors, Occasio Winery and Cannonball Wine Company, for their generosity. Finally, for their time and talents, we send a special shout out to the over 30 volunteers, event planner Kshama Perera of eWeddings and Events, our vivacious MC, Faith Alpher, from KKIQ, auctioneer extraordinaire Dennis McCormac, and our special friend Lisa Upton.

Thanks to all who attended, we raised over $100,000 this year, which is $20,000 more than in 2012. These funds will keep existing programs strong and allow for healthy growth in 2013. On behalf of the staff, members, and the board at the DSCBA, we are humbled by your generosity. See you next year!
The DSCBA held its Second Annual Empowerment Conference and Annual Meeting on March 9 at the Rolling Hills Community Church. The conference provided education and practical advice to empower our members and Bay Area educators. The morning started with an awesome continental breakfast provided by Jerry Carpenello from Fuget About It Catering; he later provided a delicious lunch as well. Once the 2013 Board Members were voted in, our keynote speaker, Mike Machado, inspired us all. He created Football Camp for the Stars to honor the contributions of his team manager, Andrew Watson, who just happens to have Down syndrome. Coach Machado wanted to create something where Andrew was going to be the guy on the field—it was time for Andrew to be the star for once. Coach Machado wanted to educate the general public about Down syndrome. Andrew also spoke at the conference, encouraging everyone to dream and to go for it!

We presented our Excellence in Education Awards, which honor people who make a significant difference in our children’s education experience. Congratulations to all who were nominated. We are lucky to have you in the DSCBA community.

Marty Barillas, DSCBA board member, father, and Chevron employee, proudly delivered a check from our friends at Chevron for $25,000. The DSCBA was awarded this Chevron Triple E award, which seeks to Empower, Engage, and Execute change in the community, to continue the work we do with families and education.

Many workshops were available, offering expertise in various areas. Workshops for parents included Get To Know your Regional Center, from Terri Bush; Understanding Sensory Challenges, from Jennifer Kroll; Negotiating a Great IEP, from Carol Cohen; From Grief to Celebration, from Martha Hogan; and Transition Years, from Gina Gourley. Workshops for educators included Total Communication in the Classroom, from Karen Baca, Kati Skulski, and Lauren Spina, and Behavior is Communication, from Hannorah Thurman. The Connection relies on the ongoing involvement of educators, therapists, and dedicated community members to provide our families with knowledge to help their child become a valuable community participant and contributor. We thank you very much for spending your Saturday with us.

Childcare was available, allowing our parents to attend the many workshops. Thank you to the Diablo Valley Chapter and the Rolling Hills Chapter of the National Charity League for providing this service. Thanks to Terese Ghilarducci, Sibling Support and Fun was available to siblings aged eight and over because they have a lot to say, too! And music therapy was offered to those who participated in child care and sibling support—thank you, Nicole Patton.

We are grateful to the Rolling Hills Community Church for allowing us, once again, to use their magnificent space. We are lucky to have you as our friends!

Another wonderful service was provided by David Yager, who came all the way from Chico to capture this magical day in photos.

We look forward to planning our next conference. Please let us know if you have any topics that you would like to hear about.

**Some quotes from attending parents and educators:**

**Educators:** “DSCBA is working hard and making a difference”; “enhancing learning as educators.”

**Parents:** “DSCBA has many programs and supports families”; “very inspirational”; “excellent workshops”; “nice to hang out with other parents.”
Fun with Numicon
Pam Wallace

I have been working with my son Torin using the Numicon system, and it is an awesome system! Initially, I had him just put the shapes in order and got him familiar with what they looked like for the grouping of 5, 6, 7, 8, etc. Before long, he didn’t need to count the holes to know the number that the configuration represented. I also had him play with the shapes and build the puzzles to get him familiar with manipulating the piece to fit. Then I progressed to where we are now. I am able to give him a number between 1 and 10 and ask him to give me 2 numbers that will add up to that number. Then he builds it by laying the pieces on top of the number he is trying to build, tells me the number sentence, ex. 4 + 3 = 7, and does it for all the ways to build that number. It is so amazing to watch him problem solve and say things like, “I need to put a 3 here” before he reaches for it. It is clearly giving him a visual representation of what, for example, 7-things look like, eliminating the need for him to count out the 7 objects and holes 1 by 1. This will make memorizing his addition facts at least mean something to him. This has been a wonderful and fun way to help Torin with his math skills.

The Numicon System is available for checkout at the DSCBA Library.

Black Belt for Michael
Paul Mariuzza

Michael Mariuzza received his black belt in karate from the Sama Academy in Pinole, CA. Congratulations, Michael!

Sam’s in the Spotlight
Cathleen Small

Sam had something fun happen: his first modeling job, for Gymboree Play and Music. He spent two mornings on set—one in footage being shot for a commercial, and one doing still shots for print ads. The commercial is currently airing nationwide.

Sincere Thanks to Our Community Supporters
Marianne Iversen

Keller Williams Realty

May 9 was RED Day (Renew, Energize, and Donate) for Keller Williams Realty, and the DSCBA was the lucky recipient of their day of community support. Each year Keller Williams chooses an organization or cause to lend a helping hand. This year they provided an amazing group of hard workers to assist us in a myriad of ways, such as preparing our classroom for the upcoming summer Communication Readiness Program, adding storage, putting new parent packs together, updating our library system, and building an amazing garden for our classes to use. Along with all of the physical labor, they also donated over $2,000 raised in their office raffle. A big thank you also goes to Rich Kelley and Mark Sypien, who assisted the Keller Williams team! It is community support such as this that keeps our doors open and our hearts full.

Thank You Keller Williams Realty, Danville office!

National Charity League

Over 45 mothers and daughters from the National Charity League (NCL), both the Rolling Hills and the Diablo Valley Chapters, provided babysitting services for our members during the recent Empowerment Conference. We send a special thanks to these NCL members who gave up their valuable time on a Saturday to enable our parents to attend the conference. We are very grateful that both NCL chapters are always so willing to help out when the need arises.

Volunteers

Every week our amazing classroom volunteers take time out of their busy lives to help in our Step Classes. Their help to the teachers is invaluable, and their friendship and peer support to students are immeasurable. We were honored to treat this wonderful group of volunteers to a dinner out to show our appreciation. A big thanks goes out to these giving individuals who help provide the quality of classes that we offer.

Thank You National Charity League, 2013!!
Tatiana, “Play Ball”
Paul Casodont

Tatiana has been selected to play for the California District 57 Challenger team, which will represent California at the Little League Baseball World Series in South Williamsport, Pennsylvania, in August. This year’s game will feature California versus the Illinois District 13 team. These two teams will represent more than 30,000 children who participate in more than 900 Challenger Divisions worldwide.

Tatiana has been playing in the Challenger league for more than eight years and absolutely loves her time on the field. The Challenger Division encourages the use of buddies with its players but also encourages players to bat and make plays themselves. In the photo, Tatiana is batting with the help of her buddy, both on and off the field, her brother Marco.

Tatiana enjoys attending baseball games almost as much as she enjoys playing baseball. Before arriving in South Williamsport, Tatiana will be attending several major and minor league baseball games on the East Coast.

All PBS television affiliates have the option of broadcasting the Challenger Exhibition Game. The game is scheduled to be played on Saturday, August 24, 2013. Check your PBS listings for viewing options!
Step Up for DS Walk Volunteer Earns Silver Award

On May 21, 2013, Marie Jimenez received her Silver Award. The ceremony was held in the Fountain Room at the San Ramon Community Center. The Silver Award is the second highest award of the Girl Scouts of the USA. It is a 50-hour service project that represents a girl’s accomplishments in Girl Scouting and her community, as she grows and works to improve her life and the lives of others. Marie’s service project was the carnival at the DSCBA’s 2011 Step Up for Down Syndrome Walk.

Gabriel Rettig

Gabriel looks forward to swimming with the Del Amigo All-Stars all year. This year he worked with Jamie and Sara. He loved the poster the girls made him and is very proud of wearing his Del Amigo swim team T-shirts.

Nico Barillas

Nicole is Nico’s Del Amigo All-Stars swim coach for the second year, and he adores her! Nicole is an extremely special girl; she made working with Nico at the All-Stars swim program one of her projects for her school’s Honor Program. We are so grateful for her generous work and patience, to Janet, and to the rest of her all stars—they do amazing work!

Little League Fun

Oliver Nakahara played on Pinole’s Little League team in the Challenger Division this year and finished up the season with a trophy.

Lucas Dillon

Congratulations to Lucas Dillon, who had such a successful experience with the Del Amigo All-Stars that he is now swimming with his swim instructors in the Del Amigo Dolphins Swim Team!

Matthew Trueblood

Matthew, second from left, after winning the All-Star time trial heat by swimming freestyle for one pool length with a time of 25.84 seconds. The Del Amigo Pool Association All-Stars program is a highlight of Matthew’s year and Matthew’s wonderful swimming coaches, JT, Matt, and Austin, were a big part of it.

Bella Lucia

Above: A constellation of Del Amigo All-Stars.
Above right: Bella Lucia, with her instructor Maddox, shines as an All-Stars.

Ainsley Dodge

Ainsley, left, and her coach, Kaylee. What an incredible program full of heart, acceptance, and spirit that Coach Janet and the kids provide for our children every summer through Del Amigo All-Stars. We highly recommend the program to everyone. Our daughter, Ainsley Dodge, loved getting in the water for 50 minutes of swimming each week, and her kicking and underwater diving improved greatly. We are so grateful for Del Amigo, Coach Janet, and all the volunteers like Kaylee.
of kids, Grace included, waiting to jump with two people swinging the rope. Mrs. Tronstad-Wardle created a system where jumpers took turns holding the rope, and she herself helped hold the rope to keep it in control. Songs then became incorporated into playing jump rope, which created more peer interaction. Grace has even learned how to double jump. Her aide and peers have excitedly cheered her on in her jumping accomplishment, and she loves to report how long she has jumped each day. Grace has drastically improved her jump rope and coordination skills. We are so grateful for Mrs. Tronstad-Wardle’s dedication, consistency, and follow through with this goal to help Grace engage with and share something in common with her peers that they all have fun doing together.

Golf Shop News from the Contra Costa Country Club

Outside staff were acknowledged by the Contra Costa Country Club this year as Employees of the Month. The Club Assistant Golf Professional stated that “Blair is hardworking and has been a dedicated employee with us since 2005.” Thank you and congratulations, Blair!

Dancing the Day Away!

Marianne Iversen

Laura Fan, owner of Synergy Dance Ballroom in Fremont, has been offering ballroom dance lessons for teens and adults at the DSCBA center. Some of the dances include nightclub two-step, rumba, and tango. They work on basic steps, underarm turns, travelling turns for two-step, two walks, progressive link, close promenade, and back corte. The students are having a blast, while staff and parents enjoy watching the end of each class to see their new dance moves. Thank you, Laura, for sharing your time and talents!

Above: Juliana Portoni and Blair Hogan
Below: Juliana Portoni, Laura Fan, Stacey Elliott, Blair Hogan

Jumping Success

Traci and Mike Cannon

It’s hard to believe our daughter, Grace Cannon, is finishing her last few days of first grade. A portion of Grace’s goals this year were focused on her social skills. As parents, we want her to be appropriately challenged and moving forward with academics, but equally as important, we want Grace to build relationships with her peers and feel that she fits into her school community. Grace’s inclusion class gave her the opportunity to meet many empathetic and friendly classmates to practice her social skills with.

One of Grace’s social goals focused on initiating, inviting, and engaging with peers to play. This goal was implemented by Grace’s aide, Mrs. Tronstad-Wardle. Grace was given the job of carrying a bag of jump ropes out to recess. She was then prompted to ask a few classmates if they would like to play jump rope with her. What started as individuals jumping side-by-side evolved into a line

Steppin’ Out and Movin’ On

Lili Byers

Olivia Byers-Straus performed a solo at her final dance recital with Steppin’ Out Dance Studio in San Francisco. This fall Olivia will move to Los Angeles where she will be a college student in the Pathway program at UCLA. For the next two years, Olivia will live in an apartment with three other Pathway students and take classes on the UCLA campus. This is a very exciting time for Olivia and her family!

Rodeo Princess

Natalie Burbach

Livermore Rodeo has a great program called “Lil Pardners” for children with disabilities. The children and their families are invited to the rodeo early to meet real cowboys and cowgirls, ride horses, rope, and play some fun rodeo games. The Rodeo Queens made Rachael feel so special. I call this picture “Rachael, Rodeo Princess!” — puts a smile on my face!

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Congratulations, Graduates!

Sean Freshley
Sean Freshley, 6 years old, completes kindergarten. He attends California Montessori Project, a public charter school in Elk Grove, CA. He loves his friends (especially the girls) and his teachers. He is successful in his inclusive environment due to the welcoming staff and solid services in place for him. With speech, OT, and a 1:1 aide, Sean has a strong support system, which helps him do his best. It’s been a wonderful year, and we can’t wait to see how much he achieves in first grade!

Nicklas Unnerstall
Congratulations to Nicklas Unnerstall! He just graduated from Metea Valley High School in Aurora, IL, walking with his graduating class. He will attend STEPS, an adult transition program, until he turns 22 years old.

Patrick Harkins
Patrick graduated from high school! He will be continuing on to a transition program with San Ramon Valley Unified School District.

Adam Ferguson
Way to go Adam! Adam Calvin Ferguson graduated from Dougherty Valley High School on June 14, 2013. He will be attending a transition program with San Ramon Unified School District in the fall.

Jackson Soderquist, Emma Yungert
Jackson Soderquist and Emma Yungert (at left) graduated from the SFUSD Community Access and Transition program. This transition program is unique because it is off campus from the high school. Both Emma and Jackson did a great job giving speeches and participating in a warm, student-driven graduation ceremony.

Megan Sudmeier
Megan Sudmeier graduates from Castro Valley Elementary School and will move on to middle school. We are so proud of you, Megan!

Sarah Sudmeier
Sarah Sudmeier and Steven enjoy the high school junior prom. Sarah was so happy on the night of her junior prom. We love you, Sarah.
Augmentative and Alternative Communication Services

What are they? When and how do I ask for them?

Karen Baca, Education Technology Specialist

Kati Skulski MS, CCC-SLP/AAC Specialist

AAC stands for Augmentative Alternative Communication and has systems and strategies to assist an individual in communicating to their maximum potential. 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; this is when a person understands more than they are able to express or say. The most common disorders that impact speech production of individuals with Down syndrome are Apraxia of Speech and articulation impairments. AAC services are provided to individuals who require AAC to communicate.

Services typically begin with an AAC evaluation completed by a Speech Language Pathologist (SLP). For individuals who are school-aged, an AAC evaluation may be recommended or requested by a member of the educational team (teacher, parent, SLP, etc.). Once the request has been made, the team often meets to discuss and determine if the request is appropriate. For individuals who are not school-aged—under 3 years and over 22 years of age—services may be provided through Regional Centers, insurance, or private practice. A report should clearly state recommendations for systems and the amount of services needed to implement the systems. AAC services are typically recommended as direct or indirect service models and are often a combination of the two. Direct services include working with the AAC user to build their competence with the system(s). Indirect services included providing trainings to the team, programming the system(s), and creating therapy materials for the individual. The individual will, ideally, have both direct and indirect services.

AAC falls under the umbrella term of Assistive Technology (AT). AT is a broad term defined as any tool or system implemented to improve or maintain the capabilities of an individual with a disability. AAC covers the systems to improve speech. Some school districts include AAC in their AT evaluation. Although this is often district dependent, it is important to be educated on the role of the SLP in the AAC process. A SLP must conduct the evaluation per Medicare guidelines (2000) when a device is submitted for insurance or Medicare funding (http://aac-rerc.psu.edu/index.php/pages/show/id/26). In some scenarios, it is appropriate for the AT Specialist to conduct the evaluation. As parents and educators, it is essential to be familiar with the laws and available services for our children.

The unfortunate reality is that there is a shortage of AAC specialists and of the institutions we have relied on for help and for financial aid. This requires us to become more creative and resourceful when it comes to obtaining what our loved ones need. 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 to parents, educators, and anyone else who is interested. We invite you to contact the Connection and provide workshops and training in AAC to parents, educators, and anyone else who is interested.

Augmentative and Alternative Communication Services

What are they? When and how do I ask for them?

Karen Baca, Education Technology Specialist

Kati Skulski MS, CCC-SLP/AAC Specialist

AAC stands for Augmentative Alternative Communication and has systems and strategies to assist an individual in communicating to their maximum potential. 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; this is when a person understands more than they are able to express or say. The most common disorders that impact speech production of individuals with Down syndrome are Apraxia of Speech and articulation impairments. AAC services are provided to individuals who require AAC to communicate.

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Jones Family  Nancy, I have started this note to you so many times but have just had a really hard time finding the right words to express how very thankful I am to you and all of you there who made sure our journey to obtaining an AAC device continued to completion. It would not have happened without you. Thank you so very much for not letting me give up and for all the help and amazing patience you, Kati, and Karen provided. Big hugs from me and Sam!

Sam’s AAC device has made it possible for him to communicate in a way that can be understood by everyone, not just me, which has greatly reduced his frustration level and the difficulties caused by it. He is also able to be more involved in the classroom and with his classmates. Since using his device, we have seen an increase in the number of words he tries to say and an increase in their clarity. The device has been a huge blessing for Sam and all those involved in his care and education.

DSEA Workshops

The DSEA is currently scheduling fall trainings and workshops. We are looking forward to hosting the following trainings at the DSCBA for educators. Please tell your education team about this training.

**DS 101:**
September 18, 2013 from 4:00–7:00 p.m.

**Behavior and Communication:**
October 23, 2013 (time TBD)

**Inclusion and Ability Awareness:**
December 4, 2013 (time TBD)

We are also happy to be invited for a DS 101 training at Brentwood Unified School District on July 24.

Visit our website, www.dsconnection.org, under the Professionals & Educators tab for updates on training and information for educators.

If you have questions or would like to get your school involved in training, please contact Nancy Ferguson, DSEA Program Manager, at Nferguson@dsconnection.org or call 925-362-8660.

DSCBA Down Syndrome Educational Alliance Update

Jennifer Cooper

Since our winter newsletter, the Down Syndrome Educational Alliance has continued to train educators by providing consults, trainings, and e-newsletters. We have also continued the process of identifying what families, students, and educators need in order to help all children succeed in school. One issue that kept resonating with (and troubling) the DSCBA staff was that students cannot possibly succeed in school when they don’t have a means of communication—and many children do not. When children can’t communicate, they cannot successfully access the curriculum and community. We have, therefore, linked the existing Expression Connection program to now fall under the umbrella of the DSEA.

This summer we are holding an eight-week pilot Communication Readiness Program for eight children entering either kindergarten or first grade in fall. What is exciting about this pilot says Nancy LaBelle, “We are not waiting on the school district to understand each child’s unique communication needs or to put supports in place.” In the eight weeks, the children will experience “going to school” (at the DSCBA) with supports in place that allow them to participate in social and academic activities. In fall, the children will be sent to school with their system for communication, which could be no-tech, low-tech, or high-tech, and a complete transition binder for the new teacher that will give recommendations for goals, modifications and accommodations. Ongoing in and out of classroom consultation and training for education teams and parents will also be available.

In addition to our work addressing students’ communication needs, we recently held trainings for both parents and professionals on specialized reading programs and the math program, Numicon. We have been talking with several educators about how to integrate the specialized curriculum into their classrooms and programs. We are beginning to see it used in resource rooms, as well as tested out at classroom centers. One district will be piloting the Numicon curriculum in a Special Day Class (SDC) classroom and a general education classroom this coming fall.

The DSEA invited educators to a special training strand at the Empowerment Conference. We had 40 Bay Area educators attend focused workshops on communication, behavior, and AAC. We have also been continuing to reach out to districts to provide their educators with the DS 101 training and ability awareness trainings in the classrooms. The ability awareness trainings are always a lot of fun, and we trained well over 500 students this year in grades K–12! The open dialogue, information, and positive perspective make such a difference in acceptance and social inclusion for students with Down syndrome.

“When children can’t communicate, they cannot successfully access the curriculum and community.”

Obviously, we’re busy and continuing to refine and develop the various components of the Down Syndrome Educational Alliance. We want to keep our families in the loop about what we have to offer educators, as you can help us to spread the word and to encourage districts and educators to take advantage of our services. We are in the process of developing a brochure for the DSEA, which will help clarify the various programs, services, and components of the DSEA. It will be ready prior to school beginning in the fall.

If you have a school-aged child, we hope it was a successful year for your child and that you feel confident about what might be coming down the pike for the fall. If you have concerns, don’t hesitate to contact us—we hope to be able to help you.
Summer DSCBA Communication Readiness Pilot Program Takes Off with Great Success

What are parents saying?

- “In two short weeks we have seen a dramatic improvement in clarity of speech in our son. He is speaking also putting two and three words together for the first time. We are so happy and excited for the unbelievable success of this first time program!”
- “Since beginning the program, our son is speaking more. For example, he is now saying, ‘I have to go potty.’ He is grabbing books from his room and opening them as if to read them; he’s very focused when he does this. I feel like this program is opening my son and our family to possibilities that we didn’t believe existed before.”
- “Our son has been consistently more vocal since participating in the CRP. We have noticed more definitive sounds. One other significant upside is the training we have received as parents. This has educated us and allowed us to continue to work with him throughout the week, while at home and on the run. We are thrilled with the direction he is taking and hope to build on it.”
- “Our daughter is talking so much more since the first week of CRP. She comments on everything around her with more descriptive words. One Sunday I was reading the newspaper next to her, and she had something to say about every picture. Her speaking volume is louder, and she has more confidence. We are so impressed with communication improvements since CRP started.”
- “Our son is talking more than ever since he started the CRP program, and we can understand him much more, too! His confidence is increasing, and he is excited when he knows he is being understood. We’re also amazed and excited because he is starting to read. He is so proud of all his successes, and we are as well. They say that behavior is communication, and we’ve certainly seen improvement in both areas.”
- “My son spoon-fed himself and ate applesauce, and read four books, following the words with his fingers.”
- “My son did excellent signs today. He asked to play by signing all by himself. He is answering my questions with yes or no, too. He is using a lot of “p” sounds.”

What the teachers and therapists are witnessing during class.

- Spontaneous use of signs like “please,” “I want more,” and “music”
- Use of speech to say u “oo,” t “tee,” and h “hah” for the letters of child’s name
- Increased use of speech, volume, and clarity
- Independently reading with repeated sentence frames
- Reading with confidence
- Identifying letters and words
- Increased participation and attention span
- Coming when called; reading and sitting; increased attention, more participation
- Recognizing child’s own name, using the springboard during activities, significant improvement in behavior and attention span
- Increase in nonverbal and verbal socialization with peers
A New Club in Town
Marianne Iversen

The Aktion Club is a community service organization sponsored by the Kiwanis of San Ramon Valley (SRV) that is open to all adults living with disabilities who want to become community leaders and provide service to the community. Paul Byer, the President of the Kiwanis of SRV, is spearheading the club with the Down Syndrome Connection serving as an advisor and supporter of this exciting new club. The members will elect officers and the meetings will run the same as the Kiwanis’ meetings.

The club’s main focus is to give back to their community while learning leadership skills, gaining confidence, developing their talents, and having fun at the same time. Some ideas that the group has come up with are to hand out food at the Relay for Life fundraiser, to help out at the Danville July 4th Parade, and to help the needy at Thanksgiving.

The Aktion Club meets on the third Wednesday of every month, from 6:30–7:30 p.m. at the DSCBA office in Danville. For more information, or if you are interested in joining this amazing new club, please contact Marianne Iversen at Marianne@dsconnection.org or 925-362-8660.

Join us for the Aktion Club Car Wash on Sept. 7, 11 a.m. – 1 p.m., back parking lot of the DSCBA. $10 per car. Spread the word. Proceeds go to club service projects.

Multimodal Communication and Therapy
Heather Peterson, MS, SLP-CCC

Over the past five years working at the DSCBA, I have learned a lot about the effective therapies for our children with Down syndrome. However, it has not been until this past year that I have really appreciated the marriage of Augmentative Alternative Communication (AAC) devices with Oral Placement Therapy (OPT). As we gear up for the Communication Readiness Program at the DSCBA this summer, I have had the chance to evaluate eight children with DS between five and six years old. I was surprised to understand that many children are without a solid primary mode of communication. Working alongside some very talented AAC specialists, it became very apparent that while we effectively treat our children’s verbal speech systems, it is absolutely necessary to give them a modality of communication and learning for the classroom and at home.

The options for this are variable and endless. The DSCBA has a grant-driven program, called the Expression Connection, that provides AAC consultations and loaner devices free to its members. Studies show that using AAC devices creates speech modeling opportunities that children can imitate and pair with a daily Oral Placement Therapy program. This is an optimal therapy plan for most of our children. One of these programs on its own is wonderful, but both of these programs combined are a price-less opportunity. Please start inquiring about OPT as early as possible and about AAC as early as two and a half years of age.

I want to leave you with something that resonated very loudly with me: almost half of our children entering our summer program have behavior plans written into their IEP’s, but almost none of them have AAC or OPT written into their therapy goals.

Please help me spread the word of this wonderful union and of the invaluable opportunities we have here at the DSCBA.

You can contact me with questions: Heather Peterson, OPT, heather@happykidstherapy.com.
Music Therapy: Making a Difference at the Connection

Nicole Patton

The Music Therapy group led by Board Certified Music Therapist Nicole Patton meets the first Saturday of each month from 10:00–11:30 a.m. for children ages birth through five. This group provides opportunities for children to work on nonmusical goals and objectives through music. Music Therapy provides a nontreathing and fun way to approach a variety of social, physical, and fine motor skills. Each month has a theme while keeping some of the same activities month to month. It is so exciting to see the children grow over the months with the familiar activities such as the parachute and the big drum. Increased social interaction is one of the many benefits that can be seen from this group. Children that come regularly each month benefit the most from this group. When we Boogaloo, the excitement that shines on the children’s faces is precious. Reading and singing books offer a multisensory approach. Music Therapy gives families a chance to interact and learn new songs and activities that they can use at home with their children. With the group meeting on Saturdays, many dads that work during the week are able to attend. Each month we go around the circle to check in with each other to see what new and exciting things have taken place since we last met. Siblings are welcome to attend.

Note: If you are interested in your child attending a Music Therapy group for older ages, please let us know. If we have enough families, we can start the program.

Stepping Out in Oakland

Virginia Bonham

Step Out took a day to walk around Oakland’s happening neighborhood, The Uptown, checking out galleries, Oakland’s new sculpture park, Uptown ArtPark, and the Remember Them: Champions for Humanity monument in the Henry J. Kaiser Memorial Park, which honors civil rights leaders around the world. We also walked over to the Creative Growth Art Center, which is dedicated to artists with disabilities. Students were able to see art created by Step Out’s own Nicole Storm. Joey called us all over as he and Athena spotted her pieces first. Her friends instantly recognized her pieces. We were all impressed by her art. Congratulations to a great Step Out year.

Harold Burns, Joseph Indresano, Athena Sjoberg, Nicole Storm, Tamika Lee

SF Step News

Harold Burns

SF Step took a break in the sun. Discussing independent living skills led us to explore Christina’s school garden and to talk about what healthy food is and what it means to become adults who can make healthy food choices independently. Becoming an adult was a hot topic this semester, as three long-time students made big steps into adulthood. This May, both Jackson Soderquist and Emma Yungert graduated from the SF Unified School District transition program, and this fall Olivia Byers-Straus heads to UCLA to continue her studies.

The SF Step group

Steppin’ Up – Fun with Butter

Laura Briggs

Look at us shakin’ and makin’ homemade butter! We poured cream into a container, added a marble for extra shaking, and then we danced away until it became butter. We put the butter on toast, bagels, or crackers. What a fun way to make yummy treat.

Above, the butter recipe. Below from left, Shawn Swienton shakin’ his butter, Anthony Godinez shakin’ to make butter, Megan Sudmeier spreadin’ the butter, Anthony Godinez and Laura Briggs.
BABY STEPS
Bringing Families Together

Martha Hogan

The Baby Steps group is one of my favorite groups of the month. It is a time that moms, sometimes dads, sometimes grandparents, and, most importantly, babies come together to meet each other, support each other, and learn about Down syndrome and its many blessings and challenges. Sometimes this wonderful group of parents also includes parents who are expecting their baby in a few months and want to get to know others who have gone before them. Recently, not only have we had support and sharing, but in March, Kimberley Lyons from Tum E Time joined us and taught infant massage to the parents. In April, Hannorah Thurman from STE Consultants helped our parents understand behavior issues and how to survive the challenges our little ones can present from time to time. And in May, Karen Baca discussed sign language and other forms of communication that can help our children express their everyday wants and needs. I feel so fortunate to help facilitate this group of wonderful parents.

Step In News

Virginia Bonham

Step In had its annual car wash at the Hogans’ to raise money for the end-of-year party. It was the first car wash for Jay, Barrett, and Tracey, but they jumped right in with the pros: Blair, K. Leigh, Stacey, Nicole, JR, and Garrison.

Benicia Step News

Brian Fruchey

The Benicia Step group was excited to get together and have a celebration for Martin’s 30th birthday. The group made individual strawberry shortcakes, which was fun for everyone! We didn’t have 30 candles, but everyone had their own candle and made a wish for the coming year. Martin loves playing host for the group and thoroughly enjoys his independence. Martin’s house is one of our favorite places to hang out.

Happy Birthday, Martin!

Sensory Fun in Small Steps

Laura Briggs

Small Steps made their own foamy finger paints with Ivory soap, water, and a mixer. Boy, was it ever fun to spread the cool, silky Ivory soap finger paint on a table, tray, and paper. It felt amazing. You should try it!

From top left counterclockwise, Aniruth Kumaran and Jaxon Mah, Lulu Jensen, and Sandro Moore, finger-painting, and showing off his sticky hands.
Next Step — Growing in Size and Relationships

Marianne Iversen

The Next Step class was added four years ago, and I have had the privilege of being the teacher since its inception. We have had the same core group from the beginning, and the growth of the students has been a delight to watch. This spring we worked on the Circles of Intimacy and Relationship Program. This program is designed to help students categorize life relationships and understand the appropriate intimacy for each relationship. Each circle represents a relationship: family, friends, acquaintances, distant acquaintances, and strangers. We had lengthy discussions on appropriate levels of intimacy for each circle—for example, hugging for family members, shaking hands or high fives for friends, waving to distant acquaintances, etc. This was a great way to learn safety and social distance along with learning more about everyone’s friends and families. Not only has there been growth in the area of maturity and development, but our class size has grown as well. We now have 12 students, and, as the saying goes, the more the merrier.

Step Out Class Poem

LOVE

Step out: Anika, Erica, Bobby, Tamika, Joey, Athena, Nicole

What is love?
Love is chocolate roses—sexy!
Love is Jack, my boyfriend, my mom and dad, like a stuffed animal, something soft
Hugging a teacher, a sister, a brother
The feeling inside of a hug.
Love is eternal
To love
Empathizing, trusting, sharing, helping out my friends—that is what loving is.
Loving is breakfast in bed, yard work for my mom, helping in the kitchen, holding hands,
Valentine’s Day!

Check website for more information: www.dsconnection.org
For questions or to RSVP before meetings, contact Marianne at 925-362-8660 or DSCBA@dsconnection.org
For Your Time, Talent, and Treasures We Are Grateful . . .

Foundations, Family Funds, and Service Organizations
Maurice Amado Foundation
Bar Foundation
Ray Benton Family Fund
Mr. and Mrs. William Calhoun
California Communications Access Foundation
Chevron Corporation
Children’s Support League of the East Bay
The Columbus Foundation
Diablo Country Club Foundation
Carl Gelbert and Celia Bert
Gelbert Foundation
Global Down Syndrome Foundation and National Down Syndrome Congress
Jam Handy Character Building Foundation
Kiwanis Club of Pleasanton
San Ramon Valley Kiwanis Foundation
Knights of Columbus Council
The Josep & Vera Long Foundation
The Thomas J. Long Foundation
Lowell Berry Foundation
Million Dollar Round Table Foundation M Squared Consulting, Inc.
Peter Musto Charitable Trust
NAILBA Charitable Foundation
Noll Foundation
Quest Foundation
San Ramon Rotary
Twanda Foundation
Wayne and Gladys Valley Foundation
Wells Fargo Foundation
Agilent Technologies Foundation
Simon Baldia Nunez
AT&T Employee Giving Campaign
Frankie Juarde Raymond Rhodes
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Paul Casadont Scott Truger
Nancy Egan
Clark Construction Group
Tim Iversen
Genentech GivingStation
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General Donations
J. H. Barr and Betty Barr
Robert Berg Laura Briggs
Karen Caetano
Danielle Chiavetta Rosemary Coleman
Eli Cooper Kevin Cunningham
Lorraine Delia Jennifer Dodge Jennifer Fischer
Barbara and Michael Gabriel
Garrett and Cathy Girvan
Julia Han
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Tim and Liana King
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Amy and Sean Parham Paul and Carol Rioux
St. Perpetua School
Gary and Susanne Sjoberg Chris and Cathleen Small
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Arti Tangri
Marilyn Tomasello
United Technologies
Steve Varnay Stacey Walls
Steve and Sharon Wilcox
Diane Wilson and Ron Beebe
Give with Liberty
John M. Najjar on behalf of Sarah Najjar
Google Matching Gifts
Vince Hang Michelle Harding
Grace Shih
Kaiser Permanente Community Giving Campaign
Wanda Haskell Gail Hibson-Lawton and Larry Lawton
in honor of Kaden Mui
Richard LaBelle for the Ruth Chiavetta Scholarship Fund
Keller Williams Danville Red Day Donations
Marianne Bordogna Ernie’s Wines and Liquors
Greg and Teresa Inchauspe
Kambiz Moshari J. S. and J. D. Ramsey
Beverly Steiner Paul Ward
Microsoft Matching Gifts Program
Howard L. Cooperstein David Williamson
Oracle Matching
Brian Eric Carlson
PG&E Corp. Campaign for the Community
Derek Kent Lleny Rios Marco Rios
Wells Fargo Community Support Campaign
Felora fatehi Paul Retig
In Honor of Caleb Adams
Ed Costa
In Honor of Hailey Bornstein
Melisa and Ernest Bornstein
In Honor of Granddaughter Katie Marie Buckman
Erika Walters and E. K. Buckman
In Honor of Robert and Connie Chin
Pearl Wong
In Honor of Jennifer Cooper with a special thanks
for doing an Ability Awareness presentation for Oliver’s class: Nada Nakahara
In Honor of Avery Grace Gordon
Jeffrey and Beverly Baus Deborah Pfau
In Honor of Barbara and Harry Gould
Pearl Wong
In Honor of Blair Hogan
Victoria and David Smith
In Honor of Jacob and Deela Hubbart
A. Lucille Brewer
In Honor of Lulu Jensen
Sommer Family Foundation
In Honor of Cole Kelley
Mary and Larry Gagnon
In Honor of Melanie McCook
Cheryl Andrade
In Honor of Ava Grace Parham and All the Angels Onstage
Jeanne and Steve Karabin
In Honor of Claire Quintella and Duggan Kerney
Ellen, Jesko, Lima, Cleine Eule Onken
In Honor of Florence and Ed Skulski
Kati Skulski
In Honor of Jared Wong
Pearl Wong
In Honor of a Beautiful Sweet Boy Named Luke
and his amazing mother: Sierra Rea
In Memory of Jim Jarrett
Mary Ann and Bob Jones
In Memory of Kyle Martinez
Geoffrey Anello Lynne Chernick
Emmanuel Cho Paul and Philip Colacico and Fleck
John Coletti Arshika Devi
Lauri Floresca Lindsay Garges
Veronica Loya Valerie McDonald
Amy Neuman Chad Nitschke
Rebecca Pearson
Mary Schust Dexter Sookra
Team San Jose Operations
Maura Weikman Tia Yang
In Memory of Steven Philip
Norman and Barbara Guest Richard and Barbara Hansen
In Memory of John Portoni
Kathy and John Harkins
In Memory of Bernard Robles
Jerry and Joyce Apostolo
Dee and Howard Folkman
Sunny Grammont
George Stegemman
In Memory of James Taggart
Mary Ann and Bob Jones
In Recognition of Claire Quintella’s Wedding
Ronald Rosequist
In Loving Recognition of Ronald VandenBergh’s Birthday
Victor and Kathy VandenBergh
Volunteers
2013 Conference Volunteers
National Charity League Diablo Valley Chapter
National Charity League, Rolling Hills Chapter
St. Joan of Arc Light Youth Group
Del Amigo Dolphins Swim Team
Teresa Ghilarducci
Dawn Handley
Lucas James
Nicole Patton
Jenny Ruz Maria Zuberi
2013 Gala Volunteers
Danville Boy Scout Troop #236
Chris Anthony Conner Anthony
Mike Arvine Marty Barillas
Jenn and Hannah Bornstein
Tracy Cannon Tami Castelluccio
Amanda Coronel Bob Cummings
Fran Cummings Maureen Cummings
Cherrell Diaz Mario Diaz
Carin Elam
Teresa Ghilarducci Christie Gillson
Kelly Herzog Jo Kelley
Gail Lawton Vesta Mistry
Patty Roderick Tabatha Roderick
Jesett Sidore
Dedicated Classroom Volunteers
K. Leigh Alfrey Aleece Cancilla
Payal Desai Nilima Desai
Lindsay Dobbis Wendy Earl
Ally Ferber Jane Fountain
Sophia Friedler Brian Fruchey
Dawn Handley Camille Hunt
Jenna Hallinger Hailey Landman
Alexis Liebowitz Macee LeMoine
Molly Napolitano Mary Logan
Logan Silliman Laura Redmond
Michela Spina
Upcoming Schedule of Events

Save These Important Dates!

August 24, 2013—**Safety Day Barbeque** in Danville (see page 15).

September 18, 2013—**Down Syndrome 101 class for Educators**, Danville (see page 13)

October 6, 2013—**Step Up for Down Syndrome**: Step up the fun at Little Hills Ranch in San Ramon. (see page 8)

October 23, 2013—**Behavior and Communication class for Educators** in Danville (see page 13)

December 4—**Inclusion and Ability Awareness for Educators**, Danville (see page 13)

December 8, 2013—Don’t miss the **14th Annual DSCBA Holiday Party**. Enjoy an afternoon of crafts, goodies, friends, and the Bell Choir. Bring your camera for a photo opportunity with Santa Claus. The entire family is welcome! This event will be held at the Los Cerros School in Danville.

March, 2014—**DSCBA Annual Empowerment Conference for Parents and Educators**, location TBD (see page 6)

May 3, 2014—**DSCBA Gala for Giving: SAVE THE DATE**

For details and updates go to http://www.dsconnection.org/

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**Bike Camp**

The DSCBA would like to host an iCan Bike camp the week of July 27, 2014, and the planning has already begun. The iCan Shine organization has had an 85% success rate teaching children with special needs aged eight and older to ride bikes independently. We are currently searching for a very large indoor venue that can also accommodate outdoor riding. If you would like to be involved with the committee or volunteer for the camp, please email Paul Crawford, our Board Treasurer, at paulcrawford311@gmail.com.

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**Medical Outreach**

Give back to the Connection and volunteer today!

**Wanted: DSCBA Medical Outreach Committee**

Please join us as we gather a committee of DSCBA family members and the community to ensure Bay Area hospitals have up-to-date information on Down syndrome and as-needed training on giving a diagnosis to new or expecting parents. If you are interested in volunteering, please call the DSCBA at 925-362-8660 and ask for Nancy, or email us at DSCBA@dsconnection.org.

(Note: This work is something you can do from home.)