



MAKING THE Connection

THE DOWN SYNDROME CONNECTION OF THE BAY AREA NEWSLETTER • SUMMER 2015

DSCBA STRIDE / PRIDE BIKE TRAINING DAY

Striding with Pride and Beaming with Smiles – A Dream Come True

Nancy LaBelle

It was a day full of pride, indeed, as 130 people, children as young as 3 to adults aged 35, received a Strider balance bike and a Nutcase-brand helmet of their very own at DSCBA's first-ever Stride /Pride Bike Training Day on July 18.

Striding with Pride → page 4



STRIDE W/ PRIDE CHECK IN HERE



Thank you Danville Children's Guild for your Support!

Thank you Viva's Banners & Signs




DSCBA

STRIDE W/ PRIDE

Thanks to Lauren Cademartori for her fun artwork for the event T-shirt

Striding with Pride photos → page 4

Making the Connection • Contents

DSCBA ASSOCIATION NEWS

DSCBA Board and Staff	2
Executive Director's Message	3
Special Thanks to the Community	12
For Your Time, Talent, and Treasures We ARE Grateful	26
What DSCBA Does for You and What You Can Do for DSCBA	28

EVENTS

Stride/Pride Bike Camp	1 & 4-9
Upcoming Schedule of Events	9
Congratulations to the Aktion Club	10
Together We Play on World DS Day	10
A Star-Studded Evening	12
Step Up for Down Syndrome	27

PROGRAMS

Medical Outreach Alliance Update	14
DSCBA Welcomes Susan and Scarlett to our Step Classes	14
Reading with Diane Viera at the DSCBA	14
Down Syndrome Education Alliance Update	15
Fall Schedule of DSCBA Classes	15
Parent to Parent Groups	15
Sharing Precious Moments	16
Music Therapy Sound Bites	16
Communications Readiness Program	17
Next Step Reaches for the Stars	17
Early Connections	18
Eli Getting Connected	19
Step In Plants with Love	19
Benicia Step's Supper Club	19
SF Step Continues to Thrive and Grow	20
Oral Function	20
Steppin' Up Shows Off Their Creative Side	21
Expression Connection Project Celebrates Four Years	21
Small Steps Experiences Messy Fun	21
Step Out, Building Community	21

COMMUNITY SPOTLIGHT

Postsecondary Success and Fun at Fresno State	22
Adiyah Sanders	23
Eli Rocked High School	23
Josias Graduated Preschool	23
Friendships are Priceless	23
Happy Birthday, Melanie	23
Haley's School Award	23
Grace's Personal Best	23
Welcome Joaquin!	24
TJ Strides with Pride	24
From Institution to Inclusion	24
Dynamite T-ball Duo	24
Superstar Vikram	24
Sam, All About Children Preschool	25
Play Ball!	25
A New Rodeo Princess in Town	25
Another Day at the Races	25



Down Syndrome Connection of the Bay Area

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www.dsconnection.org

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2015 Board Meetings

The board meets on the last Tuesday of the month. To attend or bring a guest, please contact the Board President, Mike Zolnier, at 925-819-1009 or mike@vdbprop.com. (Note: dates can change so it's best to call before attending.)

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Jen Kilian, Managing Editor
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Nancy's Notes

Nancy LaBelle, Executive Director



Hello members and friends of the DSCBA,

I hope that your summer gave you time to mix fun into your busy schedules and that you have been taking part in and enjoying events, programs, and services at the DSCBA this year. As we near the third quarter, it's time to revisit our lofty goals, understand our accomplishments, and pay close attention to where we need to be at year-end to support our budget.

I have an abundance of gratitude as I assess all that our organization has accomplished to date. I know with 100% certainty that the vital services we provide are only possible with the continued generosity of our loyal funders, local community, membership involvement, and many volunteers' hours, including our giving board of directors and a hard-working and passionate staff.

The DSCBA raises over a quarter of a million dollars a year by organizing and holding fundraising events. One of those events is the Bay Area Step Up for Down Syndrome Walk, coming up October 4, during National Down Syndrome Awareness Month. If you appreciate what we provide and all that we accomplish for people of all ages with Down syndrome, please commit to sending out a fundraising page this year. Our goal is \$150,000. Be part of our success!

Highlights of the year to date:

- Welcomed 17 new babies, many new members of all ages, and their families to our organization
- Strengthened and continued our Medical Outreach Alliance partnership with 39 Bay Area hospitals
- Developed a training program for medical professionals who deliver the news
- Organized and held an Empowerment Forum about inclusion with expert speakers and 150 people in attendance
- Delivered a Vision & Cognition Workshop for families and educators, showing the effects it may have on learning
- Celebrated acceptance while we played at Matteo's Dream Park in Concord with 250 people on World Down Syndrome Day
- Hired our second self-advocate on staff
- Trained 282 Bay Area school district educators and 70 parents about the learning profile of a student with Down syndrome
- Presented Ability Awareness training throughout the Bay Area to 834 students who have a classmate with Down syndrome
- Welcomed 225 guests at our Hollywood-themed Gala, raising almost \$120,000 for DSCBA programs and services

- Completed our first-ever Stride / Pride Bike and Training Day, giving away 150 bikes and helmets to people of all ages who have Down syndrome
- Traveled to the state capital regarding the ABLE act and continue to actively work with the NDSS regarding state and local government affairs
- Attended the Down Syndrome Information Alliance and National Down Syndrome Congress Conferences
- Added an Early Connections group for ages 0-3 on Saturdays
- Completed two summer school programs for 15 children focused on communication, literacy, and school readiness skills
- Gave the gift of communication to members through our Expression Connection technology and consultation program
- Delivered several formalized art programs within and outside of Step classes
- Hosted a Self-Determination Support Group meeting for parents of adults with Down syndrome
- Coordinated and welcomed 500 volunteers from the community for various events held this year
- Hired new Step class teachers in Oakland and Danville
- Continued to provide Music Therapy, Oral Motor/Speech Therapy, and Reading Tutoring on site
- Sponsored the ReelAbilities Film Festival
- Fielded hundreds of phone calls, emails, and drop-in visits about issues ranging from education and IEP supports to behavior or medical concerns
- Assessed our adult and aging member's needs continually, as we prepare for an Empowerment Forum on Health and Wellness to be held in February 2016
- Started planning a Summit on Aging in partnership with local Bay Area agencies
- Started preparing and trialing a Framing the Future and literacy program for adults
- So much more!

Many of you give your time and talent throughout the year and ask me how you can help. We are always looking for board members or committee members who have time to give. We need introductions to foundations or corporations that you may be connected to. If you have an idea about a function let me know.

Thanks to everyone for being part of our success!

Striding with Pride ← page 1

Ninety percent of the registered bikers had never ridden a balance bike; others had, but all were excited about receiving their very own.

This day started as a dream after reading that only 10% of people with Down syndrome ever learn to ride a two-wheel bike. It became a mission at the DSCBA to get everyone on a two-wheel bike: an opportunity to be more like their friends and family and to be filled with confidence as they learn to balance before learning the sometimes frustrating and difficult task of pedaling. The Strider folks told me that if you can walk, you can ride a balance bike. They were right!

A huge thank you goes out to the many who made this event possible. These include the Danville Children's Guild who raised the funds for the DSCBA to purchase the bikes and helmets; Keller Williams Realty of Danville who spent their charity Red Day assembling bikes, building ramps, and creating other obstacle course items; Strider for their partnership and support in bringing the event to life; Nutcase for providing a deep discount on their beautiful one-of-a-kind helmets; Vivas Banners & Signs for donating banners; and Zippy Shell of Hayward for donating two storage units. Over 120 volunteers joined us the day before and the day of the event, including the following: National Charity Leagues of Walnut Creek and Diablo Valley; Kiwanis Club; Key Club; Aktion Club of San Ramon Valley; Kovarus/Wells Fargo Race Team; boys team charity of Lamorinda; Danville Police Department; Pepperidge Farms; Jon Lucas; Golden Hills

Striding with Pride → page 6



Striding with Pride → page 6





Upcoming Schedule of Events



October 4, 2015
Sunday
**Bay Area Step Up
 for Down Syndrome
 Walk and Family Picnic**
 see page 19

December 6, 2015
Sunday
**DSCBA
 Holiday Party
 with Santa Claus, crafts,
 and goodies**

February 6, 2016
Saturday
Health & Wellness Forum
Keynote Speaker:
Dennis McGuire, Ph.D.

Dennis McGuire is a consultant in private practice and is the former Director of Psychosocial Services for the Adult Down Syndrome Center of Advocate Lutheran General Hospital in Chicago. Dr. McGuire helped to establish the Adult Down Syndrome Center, which has served the health and psychosocial needs of over 500 adults with Down syndrome since its inception in 1992. He presents regularly at national and international conferences and has published numerous articles. He is the co-author of two books, *Mental Wellness in Adults with Down Syndrome*, published in 2006, and *The Guide to Good Health for Teens & Adults with Down Syndrome*, published in 2010.

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

Together We Play on World Down Syndrome Day—3/21/15

Nancy LaBelle

Another great World Down Syndrome Day (WDS) at Matteo's Dream Park in Concord was enjoyed by the 200 people who came out. Concord Mayor Tim Grayson officially declared it WDS Day in Concord.

Members from three chapters of Lions Clubs International also attended and provided a BBQ lunch for everyone, as well as balloon animals and carnival games. Capes4Heroes gave out stuffed bears with capes to all children. Some other activities were face painting by the National Charity League of Walnut Creek and temporary tattoos applied by the Carondelet High School lacrosse team. Thank you to these groups for helping to make this a special time. And thank you for coming out to enjoy the day and celebrating with us.

See you next year!



Congratulations to the Aktion Club

A big shout out goes to the Kiwanis Aktion Club for winning the Best Community Service award as a marching group in the Danville 4th of July parade.

This service organization is in its second year and is growing in membership. It continues to provide various support and services to local organizations. Several of the Aktion Club members walked the parade this year with pride and were honored to win this award.

If you know of anyone who would like to be a member of this worthwhile organization, please contact Marianne Iversen at 925-362-8660.

It's a Match!

\$\$\$

Did you know that many corporations offer employee giving programs where they . . .

MATCH DONATIONS?

Some companies even match volunteer time with monetary donations

Check with your employer today to see if they provide matching gifts!

Vehicle DONATION PROGRAM

The DSCBA has a vehicle donation program where you can donate your car, truck, van, motorcycle, RV or boat.

Donate your Car, Truck, RV or Boat!

A portion of the proceeds from the sale of the vehicle is given to the DSCBA for our programs and services.

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

For more information or to donate your vehicle, please call 1-888-686-4483 or visit our website at dsconnection.org

Stay Socially Connected

Get updates from The Connection and learn about events
Fans can post text, photos and videos

WWW.FACEBOOK.COM/DSCBA

Don't have a Facebook account? Follow us on our website Facebook feed under the "resource" tab.

Almost 3,000 followers now. Why don't you become one too?

A Star-Studded Evening

Nancy LaBelle

This year's annual gala event was an elegant Hollywood extravaganza. Marilyn Monroe set the stage as she welcomed everyone at the entrance of the beautiful Diablo Country Club, where the paparazzi were waiting. Over 200 people attended. Many had the chance to bid on amazing auction items. These items were given by private donors and a very generous business community, for whom we are truly grateful. Guests also gave generously to our Medical Outreach Alliance with a raise of a paddle after DSCBA member Cathleen Small spoke about her personal experience and the important work she is doing with the DSCBA as the Medical Outreach Coordinator. The event raised almost \$120,000 for DSCBA programs and services.

It was also a grand night to premiere our new DSCBA movie, directed by Joey Travolta, showing our impact on our members and the

Continued → page 13



A Star-Studded Evening ← page 12

community. We were happy to have the film crew and many of the stars of the film join us to celebrate the premiere.

Our guests enjoyed KTVU's Mark Ibanez as Master of Ceremonies, with his winning personality, smile, and many fun sports stories. Mark was very generous to donate a KTVU 49er Experience and a Warriors package that raised significant money. We give a huge thank you to our Platinum Event Sponsors, Chevron and Wells Fargo, who believe in creating change within the local community. We send a warm thanks to the staff at Diablo Country Club and to Kshama Perera for once again making it an evening to remember. Thank you to the many volunteers, DSCBA staff and board members, and to all of our guests and donors! Mark your calendar and save the date for next year: The gala will be held on May 21, 2016.

PHOTOS:
NICOLE GEE
PHOTOGRAPHY
AND JACK
ARGENT
PHOTOGRAPHY

Nicole Gee
PHOTOGRAPHY
Jack Argent
PHOTOGRAPHY

Special Thanks to Those in the Community Who Give to our Organization in So Many Ways

Marianne Iversen



Above and at far right, Diablo Valley Quilters in action

Inset at left, Aggie from the Diablo Valley Quilters

Below: left, Milt Rundquist with bumpy ramp; center, Mariann Powada adding the finishing touches; right, ready for riders



Diablo Valley Quilters This tireless group continues to provide us with beautiful handmade quilts to give to all of our new babies. These are real treasures to the families, and we often hear how much they are valued and kept throughout the years. They are a true gift of love.

Keller Williams Realty of Danville For the second time, Keller Williams Realty chose the Down Syndrome Connection to be the recipient of their time and talent on their annual service day, known as Red Day. This year these incredible folks came and helped us put together 150 Strider bikes and built obstacle structures for our bike camp. It made for a rather crazy but fun day around the office! This truly was such a blessing.

Summit Financial Group, LLC (not shown) Steve Wilcox and his co-workers came to our rescue by helping to build some furniture and to hang shelves in our office and classroom. Without the help of kind and generous folks like those at Summit, these are the kind of tasks that can often go without being completed. We send a big shout of thanks to Summit for their continual support of the DSCBA.

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to support Down Syndrome Connection of the Bay Area and our community!

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Medical Outreach Alliance Update

Cathleen Small



Welcome to my first newsletter update on the Medical Outreach Alliance! A little backstory to start off: I was one of a group of volunteers doing medical outreach for Down Syndrome Connection when it was decided that we needed to devote more time and attention to it than a group of volunteers reasonably could. And so, in January I came on board as the Medical Outreach Alliance coordinator.

Since then, we've successfully made contact with the thirty-nine area hospitals that have birthing centers, and we've sent more than 400 literature packets to these hospitals for disbursement to the families that welcome a baby with Down syndrome at their facility. The packets include some basic information about Down syndrome and the resources available, and we have them in both English and Spanish versions.

We're getting a wonderful response from the hospitals we're welcoming into the alliance, and they have been passing out the materials to new families. We're also encouraging them to call us when a baby is born so that we may deliver a welcome-basket of gifts and information to the family. Several families have had the advantage of this service already.

Our outreach to the hospitals is primarily focused on families receiving a birth diagnosis of Down syndrome for their baby. Our next phase is to reach out to the area obstetricians and geneticists who are working with families who receive a prenatal diagnosis of Down syndrome. The moments after diagnosis—whether birth or prenatal—are a confusing time that many of us remember well. We hope to be able to reach the growing number of families receiving a prenatal diagnosis so that we can provide support in those confusing first days, throughout their pregnancy, and as they welcome their child to the world.

We've also developed training for nurses and other health professionals who are working with new families with a baby with Down syndrome. We hope to begin delivering that to the hospitals in our local alliance in the fall. Several of the hospitals have expressed a great deal of interest in the training, and we're looking forward to connecting with them.

I'm so excited about what's been going in the alliance over this first six months because we are forming excellent, strong connections with our local medical providers and, by extension, new families. We're becoming a go-to resource for birthing centers and hospitals when a baby with Down syndrome is born, and that's exactly what we had hoped to accomplish.

DSCBA Welcomes Susan and Scarlett to Our Step Classes

Marianne Iversen

We are happy to have added two new Step class facilitators this year. Susan Coulson has been co-facilitator Small Steps class in Danville. Susan is a terrific addition to the class and brings several years of experience working with children to the classroom. Scarlett McIntosh is our new facilitator for Step Out in Oakland. Scarlett's experience working with adults with developmental disabilities, along with her love for the creative arts, brings a wonderful energy to the class.

We are so happy to have both of these talented women as part of the DSCBA staff.



Scarlett McIntosh



Susan Coulson

Reading with Diane Viera at the DSCBA

Diane Viera



As a reading tutor with the Down Syndrome Connection, I work with students ranging in age from five years old to adulthood. I am enjoying each and every day with them.

My students have variable reading skills, and frequently adapt my methods to fit their specific needs, abilities, and reading levels.

With nonreaders, I focus on phonological awareness by practicing the blending the sounds into syllables and, ultimately, words. Vocabulary is introduced using flash cards and personal books that I create, using the model set by Natalie Hale. I have discovered that in most cases the students' favorite books are those written about their family or their special interests, thus increasing their enthusiasm and engagement in reading.

When students come to me with established alphabet and reading skills, I determine their reading level. There are three reading levels. The first level, known as the Independent Reading Level, is when a student is able to read with fluency and comprehension. The second level, the Instructional Reading Level, is when a student reads under the guidance of an educator or instructor. And the third level, known as the Frustration Level (which is to be avoided), is when the reading passage is too difficult for the student. During Instructional Reading time, vocabulary is repeatedly presented in flash cards, in leveled readers, and in the tutor-made books. Often, we also play word games—Bingo is a favorite—to reinforce the learning of vocabulary.

My ultimate goal is to instill in my clients a true pleasure and enjoyment in reading books. I hope that this will encourage them to become life-long readers. If you are interested in having your son or daughter of any age work with Diane please email her at dianec24@yahoo.com.

Down Syndrome Education Alliance Update

Jennifer Cooper, MA Ed



I continue to feel that my title, Director of Education, is too big and daunting for me because most of what we do relates to some component of education. Fortunately, we have a remarkably

talented team at the DSCBA: all are "Directors of Education" and know how to imbed education into the supports, services, and programs that we offer. From new and expectant parent supports to our Step classes, direct services, and the Expression Connection, so much of what we do is education, both directly and indirectly. And the more we educate, the more we realize that we need to educate more and that we need to learn more.

With those goals in mind, we continue to go strong in the current programs and services that Down Syndrome Education Alliance offers: trainings, consultations, information and referral services, the Expression Connection, and much more. We had a successful DS 101 training for parents in the spring, which a team from Inclusion Film svideotaped for us. Email us if you'd like a link to the video (warning, it's looong!). Parents of school-age children, mark your calendars for August 18 when we'll have Back to School—Setting the Stage for Success. This will be a parent training that discusses tangible ways to support your child's education team. Watch your emails for additional subject-specific trainings that are in the works.

As for our education, some DSCBA staff attended the National Down Syndrome Society conference in July and will be attending the Best Practices in the Education of Children with Down Syndrome conference (see PDF in Conference section of www.tbods.com) in September as well as the TASH conference (www.TASH.org) in December. Please let us know if there are specific areas of concern or interest that you want to learn more about; we'll see what resources we can gather and share.

I hope you all had a safe and successful summer—here we go again!



2015 Fall Schedule DSCBA Classes and Parent to Parent Groups

Danville Location Classes

Music Therapy

Saturday: 10:00–11:30 a.m.
Sep. 12, Oct. 10, Nov. 7, Dec. 12

Small Steps

Monday: 3:30–5:00 p.m.
Session 1: Sep. 14 through Oct. 19
Session 2*: Nov. 2, 9, 16, 30, Dec. 7, 14

Steppin' Up

Wednesday: 4:00–5:00 p.m.
Session 1: Sep. 16 through Oct. 21
Session 2*: Nov. 4, 18, Dec. 2, 9, 16
(No class Nov. 11)

Next Step

Tuesday: 4:00–5:00 p.m.
Session 1: Sep. 15 through Oct. 20
Session 2*: Nov. 3, 10, 17 Dec. 1, 8, 15

Step In

Thursday: 4:00–5:30 p.m.
Session 1: Sep. 17 through Oct. 22
Session 2*: Nov. 5, 12, 19, Dec. 3, 10, 17

Adult Classes throughout the Bay Area

SF STEP

Tuesday: 4:00–5:00 p.m.
Session 1: Sep. 15 through Oct. 20
Session 2*: Nov. 3, 10, 17, Dec. 1, 8, 15

STEP OUT (Oakland)

Wednesday: 4:00–5:00 p.m.
Session 1: Sep. 16 through Oct. 21
Session 2*: Nov. 4, 18, Dec. 2, 9, 16
(No class Nov 11)

BENICIA STEP

Wednesday: 4:00–5:00 p.m.
Session 1: Sep. 16 through Oct. 21
Session 2*: Nov. 4, 18, Dec. 2, 9, 16
(No class Nov 11)

*No class the week of Nov. 23

Parent to Parent Groups

Early Connections

(formerly Baby and Me)
For parents and their babies (infant to three years old with Down syndrome)
Facilitator: Nancy Ferguson
Location: DSCBA, Danville
Wednesday: 10:30 a.m.–12:00 p.m.
Sep. 2, Oct. 7, Nov. 4, Dec. 2
Saturday: 9:30–11:00 a.m.
Sep. 19, Oct. 17, Nov. 21, Dec. 19

Parents with School-Aged Children

Facilitator: Laurie Hawley
Location: DSCBA, Danville
Wednesday: 7:00–9:00 p.m.
Sep. 2, Oct. 7, Nov. 4

Parents with Teen and Adult Children

Facilitators: Marianne Iversen
Location: DSCBA, Danville
Thursday: 7:00–9:00 p.m.
Aug. 20, Oct. 15

Grandparent to Grandparent

Facilitator: Martha Hogan
Location: DSCBA, Danville
Wednesday: 10:00–11:30 a.m.
4th Wednesday of every month
Aug. 26, Sep. 23, Oct. 28, No Nov. meeting, Dec. 2

Parent Mentor

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

Sibling to Sibling

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

Sharing Precious Moments with DSCBA Grandparent Support Group Members



Above, left to right: Martha Hogan, Gayle Lawton, Wanda Haskell



At left: Grandparents Mason Zolnier with Grandma Kathy VandenBerghe



At left: Grandparents Keith and Wand Haskell with Ella Krikciunas when she was born



Above: Mason (left) and Major Zolnier with Grandma Kathy Zolnier



At right: Grace, left, and Grandma Rosemary Cannon



At right: Grandparents An Ra and Marvin Buchanan with baby Elise

Communication Readiness Program

Marianne Iversen



Our third summer Communication Readiness Program is underway, and already we are seeing progress from the students in the areas of school readiness skills and communication skills. This year we were able to have two classes,

Left: Andre Keenan using a speech-generating device to communicate



Above: The Roos class, reading at the end of the day. Inset: Declan Tyler matching the letter C



Above: The Roos class with an Elastablast band



Inset: Will Drucker picking up bugs

called the Kangas and the Roos, serving a total of 15 children. The incredible staff and volunteers are doing a remarkable job of keeping the children motivated and engaged in learning, through exciting tasks and curriculum. We look forward to seeing these amazing children's growth as the program completes. We are excited to be able to work with the children's fall school teams to make the transition into the new school year a success.

Music Therapy Sound Bites

Nicole Patton

Did you know?

Music therapy can enhance your child's academics, listening, social interactions, motor coordination, and language skills—all in a non-threatening and highly motivating environment. Research has shown that music therapy can benefit memory, communication, and social skills. It provides a way to tackle challenging or repetitive tasks through the use of music. Singing and rhythm offer a way to help articulate speech. Many of the children I work with here have a passion for music and a love for performance. The inherent rhythmic patterns in music can provide a timing cue to help improve motor skills. Each month in Music Therapy, we focus on a theme and utilize different songs, instruments, and activities to reinforce the theme. Social and academic skills are woven throughout the session. If you have an infant or a child up to six years old, join us in Danville on the first Saturday of each month for a great time with your child! See the schedule on page 15 for the dates.



Next Step Reaches for the Stars

Marianne Iversen

This spring Next Step worked on a project we called Reach for the Stars. Each participant traced their hand on a paper in the color of their choice. Together they brainstormed and wrote their dreams and hopes for their future on their hand cutouts. They started with the things that make them happy and what that they love to do. Then they were able to think about things that they would like to do in their future, both in the areas of recreation and vocation. Special thanks to Alyssa Lederman who helped us with this project in conjunction with her senior project at Northgate High School.



Left: Reach for the Stars Poster



Right: Adam Ferguson, T. J. Crawford, Juliana Portoni, Jane Fountain



Left: Emma Tippet, Alyssa Lederman, Adam Ferguson

Left: Vik Ramiya shows his hand

Below: The group



Early Connections

Nancy Ferguson

Early Connections is a DSCBA program that offers a friendly and supportive environment for parents and their babies with Down syndrome (infant to three years old). We share helpful information to support a baby's development. Some months we invite guest speakers and focus on specific topics. In June we invited Heather (Peterson) Vukelich, a Speech Language Pathologist who specializes in working with babies, children, and adults with Down syndrome on speech clarity and feeding development, emphasizing the relationship between the two. In July we welcomed Laura Gordon, Master Signing Times

Instructor, to discuss how the Signing Times series benefited her daughter and helped her communicate with her daughter while she was unable to speak.

In an effort to reach more families, we have added a Saturday Early Connections. This has been very well received, allowing both parents and/or parents that may be working during the week to attend.

Early Connections meets the first Wednesday and third Saturday of each month.



Welcome to Some of Our Newest Members



Jaxson



Semiya



Ethan



Morgan



Dovey



Eleanor



Eli is Getting Connected (at DSCBA): An Interview with Eli Cooper about His Ability Awareness Work

Jennifer Cooper, MA Ed

Eli, my eighteen-year-old son, graduated from Berkeley High this spring. A significant part of Eli's education has been the social inclusion with his peers and their work educating students about Down syndrome and respectful language. Being up front, honest, and positive about issues that might feel frightening, confusing, or possibly *bad* often increases positive attitudes, acceptance, and respect for diversity. Eli will continue this work next year in an official capacity with the DSCBA.



Eli, connecting to spread awareness

The following is a brief interview with Eli about his work.

- Q:** Tell me about your work here at the DSCBA.
- Eli:** Well I'm working at the DSCBA doing ability awareness presentations with my mamacita. I'm excited about this.
- Q:** Tell me about those presentations.
- Eli:** The mission is to talk about Down syndrome and to stop the use of the R-word (retard, retarded). I work on a national campaign to spread the word to end the word. I also talk about Down syndrome. I tell them that Down syndrome is not a bad thing. I tell kids to be a role model for people with Down syndrome and to help, but not too much.
- Q:** What do you mean to help, but not too much?
- Eli:** That's a hard one. Hmm . . . kids need to learn to do things on their own, so their friends need to scatter back.
- Q:** What else do you advise classmates?
- Eli:** Give their friends Diet Coke—just kidding. I tell them to be a good role model and to be a friend. Invite them to birthday parties.
- Q:** Do you do activities with the kids?
- Eli:** We do a sock activity and a marshmallow activity sometimes. That shows the effects of low muscle tone. The activities mean a lot to the kids. It gives them a chance to be included and sometimes a chance to eat marshmallows.
- Q:** Do you have parting words or a message?
- Eli:** I leave them with my personal motto, "I want to rock and roll all night and party every day!"

Step In Plants with Love

Tamara Reed

Step In had a wonderful time planting flowers for their moms for a Mother's Day gift this spring. It gave the class a great opportunity to share their feelings about their moms as they were putting the plants in their chosen pots.



Step In friends show off their flowers

Benicia Step's Supper Club

Tamara Reed

Benicia Step voted for having a summer supper club this June, and what a success it was. Different components of each meal were planned and prepped by the participants. This involved making shopping lists, going grocery shopping, prepping the food, setting up, and cleaning up—and of course, enjoying the wonderful meals. Martin's and Damien's birthdays were each celebrated by a dinner; on those occasions their parents were asked to be their dinner guests. These activities not only provide a wonderful social experience but also lend to furthering their independent living skills.



Top: Martin Gonsalves and Lisa Martin, making lasagna
Center left: Damien Carlon
Center right: Andrew Vasquez, grating cheese
Bottom: Ready to eat!

Oral Function: Why Our Children Eat and Speak the Way They Do

Heather (Peterson) Vukelich, MS, SLP-CCC



I had the pleasure of attending the National Down Syndrome Congress conference this past week and was able to provide education to hundreds of families and professionals about oral function and oral development as it relates to feeding and speech clarity. This information is so basic to our children with Down syndrome (DS) but also so overlooked and often misunderstood. I thought I would share.

Generally speaking, children with DS have some very consistent differences in the way their bodies function and process information. Children with DS are born with low muscle tone, low muscle strength, and differences in tactile sensitivity.

Muscle tone is the tension between our muscles. Children with high tone are generally tensed: curled fingers, rigid bodies. In contrast, children with low muscle tone are generally overly flexible and can be described as floppy. There is a spectrum of low muscle tone. Muscle tone is innate and does not change. You are born and die with the same muscle tone.

However, muscle strength and stability can be changed. This is why children with DS receive physical therapy in early intervention. During physical therapy, therapists combat muscle tone by building strength and stability for functional skills (e.g., sitting, standing). As you may have experienced, many exercises are used to help your child achieve those functional goals.

The last area is tactile sensitivity. Generally speaking, children born with low muscle tone and strength also display low tactile sensitivity (hyposensitivity). This can be described as *a mouth full of novocaine*. Imagine yourself the last time you received novocaine. You would never dare to eat or drink following the procedure because you might do things like bite your tongue or cheek, drool on your shirt, choke, and mismanage food. You, with sound structure and tone, would mismanage food and saliva due to hyposensitivity. Now apply that to your child who most likely has low muscle tone and strength.

This complex but logical look at our children helps explain why they eat and speak the way they do. If a child can't feel what he is doing, he will be unable to manage food, imitate speech sounds, or even manage his own secretions. If a child has weakness or instability in his jaw, he will be unable to endure the production of long sentences with accuracy of movement. When a child has oral weakness, asking him to produce sentences is like asking an untrained athlete to run a marathon. This is a set up for repeated failure.

This is just a small amount of information that is the basis for the TalkTools Oral Placement Speech Clarity program. This program was built to facilitate the hierarchy of oral development so that each child is not only able to feel her mouth, but strengthen and create stability in the correct movement patterns necessary for the production of more normalized speech and feeding development.

If you would like to find out more information, please contact me at heather@happykidstherapy.com or www.happykidstherapy.com.

SF Step Continues to Thrive and Grow

Christina Lewis



SF Step celebrates

SF STEP has been enjoying a wonderful first half of the year. They bonded more deeply as a group, discussing and celebrating each member's continued growth and successes as they navigate the waters of young adulthood. We also had the opportunity to hold several parties, inviting back old friends from previous years to come and celebrate with us in our beautiful space.



Caring for someone with Down syndrome who exhibits symptoms of Alzheimer's disease? The Alzheimer's Association in collaboration with the Down Syndrome Connection of the Bay Area invite you to attend an education and support group.

Thursday, Alzheimer's Association
October 15, 3675 Mt. Diablo #250
1:00-2:30 p.m. Lafayette, CA



Connect with other family caregivers of individuals with Down syndrome who are concerned about Alzheimer's disease.

TO RSVP or for more information please contact: Marianne Iversen at (925)362-8660 or at Marianne@dsconnection.org



Small Steps Experiences Messy Fun

Laura Briggs

We certainly love our art projects in Small Steps. And it's a good thing too! In order to make our very own individualized Brown Bear, Brown Bear books, we spent several classes finger painting with all the different colors that we would need. By the end, even those of us who don't like to get messy were finger painting right alongside those who love it. The green painting you see the kids painting became a green frog.



Will and Olivia painting their frogs



Lucas painting his frog, with Paige, a volunteer

Step Out, Building Community

Scarlett McIntosh



The Step Out community

This semester the Step Out crew worked on community building through dance and art. They reflected on one another's skills and interests to imagine what futures they would excel at. The team talked about their needs and what they felt their community would benefit from. Athena, a long-time volunteer at Food Not Bombs, talked about the necessity of community volunteers for program services in various places in the East Bay. Annika, who just finished an internship at UCSF, talked with the group about her positive experience with Project Search and her wish for more job search programs. Nicole encouraged the group to spread out and get loose with their dance moves.

Step Out talked about the health of their environment and that impact on community. Erika explained safety tips related to energy conservation.

Lastly, Step Out found a regular hang-out spot at the Sweet Bar Bakery to celebrate the end of Step Out sessions. It was also a great place to celebrate all the birthdays we had this semester. Step Out is looking forward to coming together in the fall after a relaxing and beautiful summer!

Steppin' Up Shows Off Their Creative Side

Laura Briggs

We invited our wonderful art teacher, Alice Pennes, to spend a few days with us. We were so excited when we found out we were going to make homemade Shrinky Dinks!

We used permanent markers to color in the plastic cutouts of birds and leaves that Alice brought in. Then we painted on a special mixture before we put them into the oven. We were able to watch as our plastic pieces shrunk to itty-bitty pieces, right before our very eyes.

After stringing them into a beautiful long chain, we hung them in the front window of the Connection. Please stop by and marvel at them the next time you are around, before the students get to take them home!



Jonah, with Camille, in front of completed birds



Left: Michael, Rohan, and Nina painting their birds



Right: Nina stringing her birds

Expression Connection Project Celebrates Four Years

Kati Skulski, M.S. CCC-SLP



The Expression Connection Project (ECP) recently celebrated its fourth year at the Down Syndrome Connection—time is flying! It has been a true honor and personal accomplishment to be part of such a beneficial and worthwhile program. ECP continues to build its AAC (Augmentative and Alternative Communication) lending library and provide consultation to students, parents, and professionals. In addition to consultation and lending services, ECP provides trainings, monthly communications, and AAC resources on our website (<http://www.dsconnection.org/augmentative-alternative-communication.php>). ECP also collaborates with the CRP (Communication Readiness Program).

Since January, ECP has provided consultation to 19 families and 7 professionals. Many of our consultations have resulted in collaboration between home and school for the implementation of AAC—a gold standard in best practices. While AAC is often put in place during school age-years, at CRP we also serve individuals from birth to three years old and into adulthood. If you have any questions regarding AAC and ECP, please contact Kati Skulski at 510-381-9992.

Postsecondary Success and Fun at Fresno State

Mary Erickson

Congratulations to Marissa Erickson for completing two years of postsecondary education at Fresno State's The Wayfinders Program. Wayfinders is an inclusive, postsecondary, independent-living program for students with intellectual disabilities. Marissa took advantage of all the program had to offer and enjoyed living in student housing, taking university classes, and working gainful employment. She is looking forward to moving back to the Bay Area and staying in touch with all her classmates.



A: The best thing about living in Fresno is getting to see all of the community. Some of my favorite community outings involved animals in the parks—like dogs at the dog park.

Q: Was there anything you did not like about living in Fresno?

A: I did not like seeing homeless people begging for money and food. I feel like I want to give them food to eat. I did not like seeing them on the streets, and I wish they would go to a homeless shelter.

Q: What advice would you give new students?

A: I would give them the advice to listen to the Independent Living Coordinator when it comes to money, budgeting, and using your credit card only for a good reason.

Q: What accomplishment are you most proud of?

A: I am proud to be attending the Inclusion Film Workshop Program starting this fall.

Marissa answered questions about her experience at Wayfinders.

Q: What did you like most about attending Wayfinders?

A: I like Wayfinders because it has been helpful to learn how to live by yourself.

Q: What were some of your favorite activities?

A: My favorite activities were hanging out with my friends from Wayfinders, going to music concerts, shopping, and seeing other fun activities in the community.

Q: What was hardest about living in your apartment on your own?

A: The hardest part was doing my chores by myself, which included cleaning my laundry, my bedding, my room, and the living room.

Q: Did you get homesick?

A: One time I was homesick, and I missed my mom a lot. I didn't want to go to the Wayfinders because it was so hard to—leave because my mom is my best friend, and she is my angel. I love my mom with all of my heart and with having DS, I am so happy to have a mom in my life.

Q: What classes did you take?

A: At Fresno State I took a Hip Hop dance class and also an art class that I loved a lot. I worked so hard on my homework for my classes that I got all As. I just love Fresno State!



Marissa graduates from Wayfinders

Q: What was your favorite class?

A: My favorite class was the Hip Hop dance class. I like to dance and to feel the beats of different kinds of music.

Q: Did you have a job while at Wayfinders?

A: While at Wayfinders, I worked at Colorado Grill. I did chores like cleaning the restrooms, cleaning the trays, and taking out the trash. I loved my job at Colorado Grill and my boss, too!

Q: What did you like best about living in Fresno?



Eli Rocked High School

Eli Cooper

Eli graduates from Berkeley High School



Eli received a special certificate for his leadership and citizenship throughout the school year.

Preschool Graduate

Dean McCook



Melanie McCook turned five and graduated from preschool!

Josias Graduated

Stephanie Segundo

Josias graduated preschool. Next stop: TK!



Adiyah Sanders

Norlisha Long

Adiyah Cymone Sanders, 18 years old, recently graduated from Alameda High School in Alameda, on June 12, 2015.



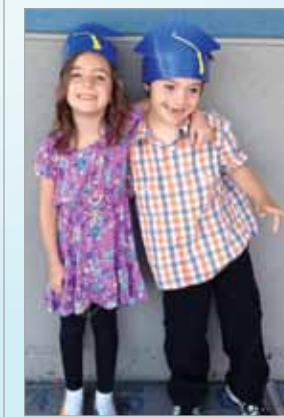
Adiyah was one of four students in the senior class to receive an award for Outstanding Personal Achievement. We are very proud of her!



Friendships Are Priceless

Rita Rebello

Garrett graduated from kindergarten. He worked very hard on his academics and made great progress in the General Education classroom. But the friendships he has made this year are priceless. We are so proud of him.



Garrett with his sister, Serina

Haley's School Award

Brooke Wollesen



Haley Wollesen currently attends Lydiksen Elementary school in Pleasanton and is fully included in her third-grade classroom with a full-time aide. Every month each third-grade teacher nominates one student who demonstrates that month's character trait. In January, Haley was nominated by her teacher for self-discipline. The principal honored her at a school-wide assembly and said, "Haley is diligent in working towards her academic goals!" Haley was so proud of herself for getting an award. Good job, Haley!

Grace's Personal Best

Traci Cannon

Grace Cannon finishes off her third grade year by being awarded with the Student of the Month life skill, Personal Best, awarded by her inclusion teacher, Mr. Slater. Throughout the school year, one student from each class is awarded with the life skill of the month, so it is a special honor. Grace was too afraid to go on stage to accept the award; however, she was very happy showing off her certificate and medal afterward. She also got to have a pancake breakfast with the principal. After eating



Grace shows her certificate, with proud parents, Traci and Mike

her pancakes she turned to the principal and said, "So now what, am I in trouble?!" We think she was kidding?! We love you, Grace! Love, Mama, Papa, and Brady.



Joaquin at 9 months

Welcome Joaquin!

Hillary Vivas

Luis and Hillary Vivas welcomed baby Joaquin into the world on August 5, 2014. Joaquin has had quite a year. He had five surgeries and numerous other medical procedures. However, when you meet him, you would never know he's been through all of that; Joaquin is a very happy, active, and delightful baby! Luis, Hillary, and Joaquin are grateful to be part of the DSCBA family.

Dynamite T-ball Duo

Laurie and Danny Hawley

Liam, nine years old, played with his younger brother, Carter, on the A's T-ball team. We are so grateful that the Delta Baseball & Softball League was flexible and allowed Liam to play T-ball even though he has aged out. It was a great season, and Liam fit right in.



Liam, right, with Carter

Another Day at the Races

Marianne Iversen

For the second year in a row, DSCBA was the lucky recipient of a donation from the Oak Tree Racing Association. To collect the check, some of our Next Step and Step In class participants, and Executive Director Nancy LaBelle, were driven in a Clydesdale-drawn carriage up to the finish line of the race track

at the Alameda County Fairgrounds. We were a proud part of the flag-raising ceremony, while the national anthem was sung. We are extremely grateful for Oak Tree's continued support and for their generous \$2,000 donation.



Above: Waving from the carriage



At left: And off they go

Play Ball!



Emma Tippet loves playing Challenger Baseball. She is on the Senior San Ramon Yankee team.

SuperStar Vikram

Prem Ramiya

Vikram had a very good Special Olympics season this year. He first won a gold medal in Special Olympics Basketball as a member of the



San Ramon SuperStar Vikram

San Ramon SuperStar team and then won two Special Olympics medals in the Oakland swimming event.

TJ Strides with Pride

Tim Crawford

TJ wanted to learn to ride a bike at 19 years old. Through the Down Syndrome Connection Strider Bike Lending Program, we picked up a Strider bike last December. TJ started learning to scoot and steer the Strider bike in an open parking lot. He picked up both skills within one or two outings. TJ practiced for about 15 minutes once or twice a week. After he was comfortable steering and balancing, we introduced braking—an important skill! The next six to eight practice times, TJ worked just on those three skills: balancing, steering, and braking. Next was trying to go down a slight downhill. TJ showed he could handle all the skills he had learned and looked like he was ready for the last big skill, pedaling. TJ took off on a 24-inch pedal bike and started pedaling like he was born to ride!



TJ makes the rounds with his wheels



Now TJ rides to 7-Eleven (for slurpees), his grandparents' house, the hardware store, the pool store, and the bike trail—just one more activity to do with his family and friends. Yeah, TJ!

A New Rodeo Princess in Town

Natalie Burbach

Livermore Rodeo has a super program for children with disabilities called Lil' Pardners Rodeo. The children and their families attend the rodeo and get to meet real cowboys and cowgirls, ride horses, play fun rodeo games, and have lunch. It is always such a great experience for Rachael.

This year before events started, they announced that they were going to crown a Lil' Pardners Princess. The princess would ride in the opening ceremonies on the Livermore Stage Coach. The envelope was passed, opened, and read: this year's Lil' Pardners Princess was Rachael Burbach! A



crown was put on a cowgirl hat and placed on Rachael's head, then the sash. Oh, my gosh—was Rachael excited! I had the honor of riding with Rachael on the stage coach. Rachael waved at thousands of people cheering as we rode around the arena. What a day! The people that volunteer and work at the Livermore Rodeo sure know how to make kids



feel special. Miss Livermore, Bailey Laughlin, was such a sweet partner for Rachael. What a great role model. Thank you, Livermore Rodeo and Lil' Pardners, you rock!

From Institution to Inclusion

Kelly Huff



Katrina

bring into our family almost one year ago. Katrina's biological family relinquished their parental rights after birth when they learned she had Down syndrome, leaving Katrina to spend her young life in an Armenian orphanage. Her life experiences there were largely confined to a 20 by 40 foot room. She was completely isolated

and excluded from the world outside the orphanage walls. My husband and I, who already have a child with Down syndrome, wanted to help another child with DS have a chance at a fully included, meaningful life—and so began our worldwide search. We found Katrina through the Hopscotch Adoptions Down Syndrome Adoption program.

Since we brought Katrina home in August, 2014, she has made tremendous strides. It is clear that she loves her freedom and newfound ability to explore the world. It's amazing to see her blossom right before

our eyes. We are not going to let anything or anyone ever again limit the possibilities life has to offer her and are paving the way for a fully inclusive life experience for her. She has just been enrolled in regular preschool where she will be fostered in her development just like every other kid, with caring teachers who will also support her learning differences. She is just one of the kids in our community and is having a pretty normal childhood. There's nothing special about anything segregated (education, living, work, etc.); we are going to continue to provide Katrina with the inclusive life experience she deserves.

Sam—All About Children Preschool

Cathleen Small



Sam, flying high

Sam Small turned three in February and transitioned out of his Early Intervention program at We Care in Concord. Although he misses the wonderful teachers and friends he made there, he is doing beautifully in his preschool program! Sam's mom worked with the school district to have him placed in a private general education preschool, and he is rocking it! As hoped, his speech is developing by leaps and bounds now that he's around all those fun peer models! Sam has made good friends and loves his teachers at All About Children Child Development Center.

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IN HONOR OF CLAUDIA YOUNG

*And her love of teaching our children
A gift beyond measure. From the
PALS 5th grade class of 2015
Rachell Cashion*

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IN LOVING MEMORY OF MY PARENTS

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Volunteers → page 27

Volunteers ← page 26

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Team

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Go to the **Programs/Events** link and learn about DSCBA activities, and also note the **Upcoming Events** calendar below

Peruse DSCBA's facebook feed, the **Connection** newsletter and more, at the **Resources** link

Share the **Professionals & Educators** link with educators and other professionals who can benefit from DSCBA alliances in the community

CONNECT WITH THE DSCBA
Support its services—or use them, or both—and you will treasure your connection as a positive force in your community.