

20th Anniversary Edition
Making the
Connection
Volume 11 No. 1 · March 2018



Catching Up with Our Friend Jay

By Cathy Purchio

My brother Jay, now 65 years old, is a great example of how to stay active and fit as we manage the aging process. We're very grateful for the help and support that the DSCBA has given us along this journey.

Jay's life and health improved greatly when he took an interest in walking and jogging the three-mile loop around Lake Merritt in Oakland. He started by watching others and slowly trying to jog; soon he was able to run the distance and improve his form. We were regulars out there for years. In 2011 we added Lake Chabot to the mix, doing the four-mile half loop. Jay met so many people and loved getting high fives from fellow joggers.

Sometime in 2012 I wanted to add another activity in Jay's life, either a tutor or a class, and found the DSCBA. Jay was 59 years old at the time, and I was hesitant since he hadn't been in a classroom setting for some time. I read about the DSCBA activities available for toddlers to adults, but would they offer services to someone of his age? Yes, indeed! The DSCBA turned out to be just the right place.

Right from the start, Jay was asked to bring in some of his favorite photos.

Our Friend Jay: see page 2

CULTIVATING A COMMUNITY

Growing older has its ups and downs for everyone. Adults with Down syndrome as well as their families and caregivers need a support network to help celebrate victories and offer guidance during challenging times. Remember to reach out for help and stay connected.



Jay, wearing his tie-dye art



Jay, left, with Joe, his twin brother

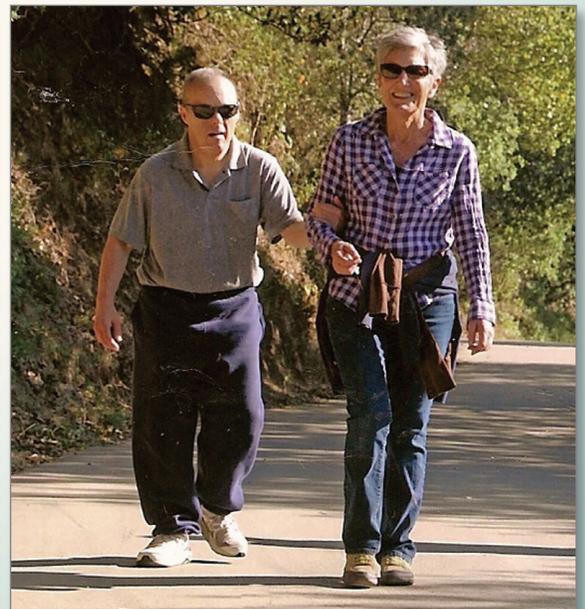
Pounding the pavement



Jay with friends at Lake Merritt



Jay and Cathy at Lake Chabot





Nancy's Notes

Nancy LaBelle

Happy Spring! I wish you all a healthy and happy 2018.

Thank you for your support in so many different ways throughout 2017.

If you volunteered, donated, or raised funds, you gave us the opportunity to sustain our vital one-of-a-kind programs and welcome 56 beautiful new babies and their families in 2017. Your support allowed us to empower and connect hundreds of families, teachers, and medical professionals throughout the Bay Area. We simply cannot do what we do without all of you.

This year we celebrate our 20-year anniversary of the formation of DSCBA. It also happens to be my 10th anniversary as executive director, which is a good time to reflect on the significant impact we have made as an organization.

When I took on my new role 10 years ago, I didn't know much about Down syndrome or how our members were being welcomed or accepted in the community. As I made my assessment in 2008, it became very clear that there were many areas pertaining to basic human rights needing significant change as well as significant opportunities to change mind-sets and to break down barriers. Opening doors to opportunities and providing services that lead to independence and development were on the short list.

Walls that were up in Bay Area schools 10 years ago have come down because of the partnership we have created by providing training and support. This partnership has opened doors to both inclusive and quality special education settings. There is still much more work to do, but we are proud of the doors and minds we have opened.

Nancy's Notes: see page 3

Jay in 2010



Jay works on a Valentine's project



Happy 60th birthday!



Fun with painting

At right:
Jay strikes success at the bowling alley

Below right: Jay at the bowling alley



Our Friend Jay: from page 1

Nancy LaBelle turned his photos into a personal book, which is now a worn and cherished collection of his special memories and interests. Jay was offered an iPad and the opportunity to work with Kati Skulski on his communication. I knew then I had better stockpile thank you cards because I would be thanking the DSCBA staff every time we entered the building. There was always something positive to offer Jay, whether it was activities or information. I enrolled Jay in a Peer Development class (formally known as Step classes). Jay has always loved music but would only lip-sync to songs. I could never get him to dance. The peer group got him dancing! He loved it. From there I signed him up for tutoring, where he worked initially with Kathy Miles and later with Diane Viera. I have always felt Jay was in a special place where they really got him—and he felt it too.

Recently Jay has been experiencing health setbacks. In 2014 our goal was to get Jay up and moving again so he could continue at the DSCBA. When he finally was able to attend Peer Development class again, DSCBA provided a volunteer to work with Jay. We also returned to the tutoring classes that Jay loved. Unfortunately another setback occurred in July 2017. Jay continues to deal with health issues related to aging with Down syndrome.

With this, the DSCBA has been extremely helpful again, connecting us with other families with older loved ones going through similar situations (via the Online Family Caregiver Support Group). The DSCBA also has an impressive network of resources for specialized medical information. I'm hoping Jay will be back again to pick up where he left off and join this wonderful community again. The Down Syndrome Connection has been a lifesaver for Jay and our family, and we will always be grateful.

Nancy's Notes: from page 2

Our Medical Outreach Alliance training with Bay Area hospitals has changed the way families are receiving a diagnosis and is also providing them with up-to-date information. Medical professionals are getting the support and information they need in order to have a difficult conversation and that includes understanding the vast abilities of people with Down syndrome of all ages.

I have had the honor of seeing many of our members grow from little ones to teens and from teens to amazing young adults. Our adult programs continue to provide a very important, unique outlet for peers to share with one another; the friendships that are created are long lasting and invaluable.

Our staff remains committed and dedicated to doing the work necessary to make this world a better place for all people.

Thank you for your support of and trust in me these past 10 years and for your generosity that keeps us going strong.



Events

HOLIDAY PARTY 2017

Teresa Schaub

Once again, the Down Syndrome Connection of the Bay Area brought holiday magic to children and families from all over the Bay Area!

Families came together to enjoy a stress-free afternoon of celebration, holiday festivities, fun activities, social connections, and delicious desserts followed by some special performances. The Bell

Choir offered an abundance of musical energy, pure joy, and happiness!

A stage full of enthusiastic individuals came together to create musical masterpieces using a collection of colorful hand-held bells.

The performance was guided

by DSCBA Music Therapist Nicole Patton. Rachael beautifully graced the audience by playing the piano and singing several favorite holiday songs. K. Leigh delighted everyone as she elegantly performed holiday classics on the clarinet.

It was a wonderful day meeting many of our new babies, welcoming several new families, and reconnecting with old friends. Our annual membership party was a spectacular holiday event, which included a surprise appearance from Santa and his elves. It was a magical day for all at the DSCBA!





Step Up for Down Syndrome Makes Goal of \$210,000 for DSCBA Programs

Kshama Perera and Melissa Benavidez



Sunshine and smiles were abundant during the annual Step Up for Down Syndrome Walk & Family Picnic on October 8, 2017, at Pleasant Hill Middle School. A record 1,400 walkers enjoyed an afternoon of fun and entertainment after "stepping up" their fundraising efforts to raise our goal of \$210,000.

The walk kicked off to the music from Las Lomas High School's pep band, a cheer by Carondelet High School's dance and cheer squad, and an uplifting speech from special celebrity guest Megan Bomgaars from the TV show "Born This Way." Megan also had a long line for autographs at her booth where she sold her Don't Limit Me T-shirts.

DJ Joey provided the festive music, which, of course, resulted in dancing later that afternoon!

Each team received a professionally printed team sign donated by Don Gardner of SPK Associates to carry along the walk. Key accomplishments were recognized for walkers with Down syndrome at the finish line, garnering cheers and applause from the sidelines. Huge thanks to our friends from the Golden Gate Garrison 501st Legion and the Avengers who gave out medals and took pictures with our walkers.

Plenty of grassy areas made the perfect setting for family and team picnicking

Step Up: see page 5



Step Up from page 4

afterwards—with food trucks, a coffee bar, and an ice cream stand available. Attendees were treated to free carnival games, cotton candy, face painting, and miniature golf among other lawn games.

Special thanks to our gold sponsor Macy's for their 5th year of sponsorship and to Scott Ferguson, Macy's district vice president, and Kia Panah for bringing their team to hand out prizes and gift cards. We are also very grateful to our other gold sponsors, John Muir Health and Fremont Bank Foundation, for their partnership this year.

We would like to acknowledge and thank all of our advertisers, donors, and supporters: Eternal Water, FarWest Sanitation & Storage, Recycling4Smiles, Pleasant Hill Orthodontics, Quest Foundation, SPK Associates, Vivas Banners & Signs, West Coast Avengers, Golden Gate Garrison 501st Legion, and Taste of the World Market.

A big thank you to everyone who raised funds this year! Over 2,000 generous people from around the world donated and made our goal of \$210,000 because of the 188 families who created a page for fundraising! Top honors for fundraising go to the Peninsula Team with a record-breaking \$20,000; Nico Tom and Julie Tang brought in \$7,100 and \$6,600 respectively. The top six teams raised over

Step Up: see page 6





Step Up: from page 5

\$68,000 in funds and include Peninsula Team, Team Drucker, Team Leah, Dubh Nation, Team Friends, and Glam Grace. The award for the Most Team Members went to Team Drucker with over 200 members, and the award for the Most Creative T-shirt Design went to Team Chromies. Julie Fuqua of Julia Fuqua photography and Lisa Upton of Lisa Upton Photography kindly donated their time and photography talent, taking many beautiful candid and team pictures.

Nearly 200 volunteers from leagues of Walnut Creek and Lamorinda helped staff the event and kept it running smoothly. There was a wonderful spirit of support and encouragement all day, celebrating abilities and promoting acceptance.



See you at *this year's*
Step Up for Down Syndrome
 walk on **SUNDAY, OCTOBER 7, 2018!**



A big thank you to photographer Kevin McGladdery for his generous offer to take free photos of our beautiful members. If you need a photographer, please consider KMCG Photography.

<https://kmcg.photography>

Email: kevin@kmcg.photography
 Tel 616.304.2161



K M C G

Expression Connection Services in 2018

Kati Skulski



This year is a time of refocus and restructure for the **Expression Connection**, a DSCBA-sponsored program that aims to bring communication systems, strategies, and techniques to individuals with Down syndrome or Down syndrome/Autism Spectrum Disorder as well as those who serve them. New this year, the DSCBA will offer a menu of services through Consultant and SLP/AAC Specialist Kati Skulski for Augmentative and Alternative Communication (AAC) and Assistive Technology (AT). Services are designed to meet families and teams at all levels of providing communication systems and support for those who need more ways than just speech to communicate. Assistive Technology services will explore more independent ways to access curriculum such as reading, writing, and math. Services will be fee-based and can be provided at the DSCBA office in Danville or in the individual's home, school, or community environments. Limited scholarships will be available for DSCBA members who apply.

SERVICE OFFERINGS AVAILABLE

1. **Referral:** A free 30-minute phone consultation regarding the needs and questions of the client.
2. **AAC/AT Introduction:** A meeting of up to two hours with team members to explore equipment at the DSCBA's Lending Library that supports communication, reading, writing, and math.
3. **AAC Evaluation:** A comprehensive evaluation of up to 20 hours utilizing the individual's full communication capabilities (nonverbal, verbal, and aided communication). The assessment includes collaboration with all team members (home, school, community), system/device trials, formal and informal testing, etc. Recommendations for communication systems, goals, services, and an intervention plan will be provided.
4. **AT Evaluation:** An evaluation of up to 20 hours regarding specific challenges with traditional writing tools, written language composition, reading, math, and organization. The assessment includes collaboration with all team members (home, school, community), system/device trials, formal and informal testing, and more. Recommendations for AT tools/systems, intervention plan, goals, and services will be provided.
5. **Implementation Consult:** A consultation for individuals and teams who have systems and tools but want support integrating them into the individual's day to day routine, whether that is in school, home, work, or other.
6. **Action Plan:** Develop a plan to implement recommended tools and strategies.
7. **Coaching:** Learn about evidence-based partner strategies, teaching tools, and methods that facilitate use of AAC and AT tools.
8. **Tech Support:** Learn how to use, program, and feel comfortable with AAC and AT technology.

RESEARCH NEWS

Thanks to ongoing support from the Disability Communications Fund, the DSCBA was afforded the opportunity to conduct research on the outcomes of our summer Communication Readiness Program. The project, titled "Outcome Study: Instructional & Interactive Strategies and Communication Behaviors of Children with Down Syndrome," has been shared at the following national conferences: American Speech-Language-Hearing Association (ASHA); Down Syndrome Affiliates in Action; and Prentke Romich Company's AAC Journal Club. Keep your fingers crossed for acceptance into the International Society for AAC's (ISAAC) conference, which will take place on the Gold Coast of Australia. It's our goal to share these strategies and, with you, to support communication in all environments!

Email Kati at kaskulski@gmail.com for information about fee structure, scholarships, and to learn more about the Expression Connection program benefits.

Down Syndrome Connection of the Bay Area
Connecting Families for 20 Years

20th Anniversary Gala

SATURDAY, APRIL 14, 2018
FROM 5:30PM TO 11:00PM
DIABLO COUNTRY CLUB
FORMAL COCKTAIL ATTIRE

Join the DSCBA and Master of Ceremonies Mark Ibanez for an elegant evening that includes dinner, fine wines, amazing auction items, dancing, inspiring stories, and more about the impact of the Down Syndrome Connection over the last 20 years.

Kindly RSVP by April 1 at dsconnection.org/gala




Twenty Years of Learning and Friendships ... Then and Now

Marianne Iversen

"I appreciate the fact that my son has a chance to interact with his peers who also have Down syndrome, since he goes to a school where he is the only child with Down syndrome and there are no other children with developmental disabilities in his general education class."

"My son continues to develop his independence, leadership skills, and confidence through this class."

"My son looks forward to this class every week; it has helped him advance socially in a fun and positive way."

— Quotes from Parents

Our classes, originally known as Step classes, began at the inception of the DSCBA and were primarily developed by Katherine Sefton, MDT. The classes were started to provide an environment in which younger children with Down syndrome could work on areas where they might be developmentally behind their typically developing peers. Academic enhancement with a strong emphasis on fine motor, visual motor, and sequencing were the primary focus. At that time the emphasis in the teen classes was placed on abilities first, then individual empowerment, friendship-building, group affinity, and community responsibility. Now, twenty years later, the classes are called Peer Development classes and remain an essential program that we provide. In some cases participants who were in the younger classes at the beginning of DSCBA are now in our adult classes. We currently have nine classes in six Bay Area locations, serving ages four to sixty-five. The original goals of the classes remain.

The classes have proved to provide a safe environment for learning, sharing and, perhaps most importantly, offering a space for the participants to be their true and authentic selves. So many of our classes have members that have been together for many years; these connections and friendships play a significant role in their lives.



Laura Briggs (top) and Tamara Reed were two of the first DSCBA class facilitators. They have both taught several different classes throughout the years. Laura now facilitates the Tween/Teen class in Danville, and Tamara continues to facilitate the class for adults in Benicia.

Then



I like seeing my friends every time."

— A Participant

At left and below: Tuesday teen and adult class then and now

Now



Then



Above and below: Oakland's adult class then and now

The winner is ...
Best 2017
Teen & Adult
Program
See page 3 for details.

Now



"My daughter relies on this class as a place to share what's going on in other areas of her life and mentions that at least once or twice during the week."

"I can always count on the classes to be a safe environment for my son to participate with age appropriate peers—safe both environmentally and emotionally."

— Quotes from Parents

Then

"I like it, it's fun."
—A Participant



At right and below: Thursday's adult class then and now

Now



Now

Above: Patrick Harkins showing off his abilities on the balance steps



Then



An Alliance Focused on Communications

Jennifer Cooper



As the DSCBA turns 20, my son Eli turned 21. Our family has been connected with the Connection (as members and as staff) for all of those 20 years. One of the many changes during that time has been our positioning regarding the education of children with Down syndrome. While we've always supported the families navigating the educational maze for their children, we

didn't support the educators who were spending many hours a day with those children. The Down Syndrome Education Alliance (DSEA) was created 8 years ago to fill that gap in services.

The purpose of the DSEA is to provide information, resources, and supports to the educational teams (parents included) working with students with Down syndrome. We have created and facilitated numerous in-person trainings and provided those trainings to thousands of educators and parents. We have Facebook groups, educator mailing lists, lending libraries of curriculum and technology, and more. We are a valued resource for parents and educators alike to learn information

about best practices supporting their students with Down syndrome. We continue to learn more, challenge ourselves, and strive to incorporate the diverse needs of our members.

We know there is no one best model, and yet we believe strongly in the right to and research about the benefits of inclusive education. When appropriate and desired by the family, we aim to have students with Down syndrome included in general education classrooms. Providing educators the proper supports and information to allow students with Down syndrome success in the classroom is a driving force of the DSEA. A critical piece of that goal is ensuring students have a voice in the classroom. The focus on communication in all forms has been a main focus of the DSEA and programs within it. As we say, "If you can't communicate, you can't participate," so we strive to ensure that all of our members have a means of communicating their needs.

In addition to giving children a voice, we also aim to empower parents and educators. Because we cannot provide one-on-one consultation and guidance for every family and student, the goal is to educate through our website, our Facebook feed, our in-person library, meetings, and trainings. If you do not already receive our emails, please go to the "Get Involved" tab on our website and click "Become a Member." We look forward to working with you!



Dear ELI in my opinion You should Be a Teacher! Another reason is That you DID a good JOB! We can MAKE a Change!

Kids notice differences at young ages but don't typically have the language or capacity to discuss those differences. If they're outspoken, children might eventually question the age or obvious differences in behavior or language of their classmates with Down syndrome. When adults in the community ignore these differences, instead of showing acceptance, it implies that it's a hush-hush topic—one that must not be okay to discuss, one that must be negative

Ability Awareness: see page 11

**Left: Letter of appreciation from a student
Below: Jennifer and Eli raising ability awareness**

ABILITY AWARENESS

Celebrating Differences in the Classroom

Jennifer Cooper

Fifteen years ago, when I proposed giving my first ability awareness lesson to my son Eli's first grade classroom, I was met with resistance. The school questioned whether directly pointing out Eli's Down syndrome was necessary and was of the mind-set that it might do more harm than good. "Why point out his differences? Can't we just treat him like the other students; we don't point out their differences." Their thinking was coming from a place of kindness and acceptance, but was also coming from an idealistic and unrealistic perspective.





Medical Outreach

Cathleen Small



Almost six years ago, when I had my son with Down syndrome, I left an East Bay hospital with virtually no information—just a scrap of paper with RCEB.org written on it, and vague instructions to “contact them—that’s the Regional Center.” There was no mention that just a short drive away, there existed an organization solely devoted to empowering, inspiring, and supporting people with Down syndrome, their families, and the community that supports them.

I stumbled upon the DSCBA through a simple Google search, and I was dumbfounded that the hospital hadn’t bothered to connect me with them—it was only by luck that I found them! I wanted to change that for families coming after me, so I came on board as the Medical Outreach Alliance coordinator in 2015. Since then, we’ve formed relationships with 39 Bay Area hospitals with birthing centers. We’ve met with social workers, nurses, pediatricians, genetic counselors, and geneticists to make sure they do know about the DSCBA and all the services

and supports we provide, so that when future parents welcome their child with Down syndrome, they will be connected to us immediately.

We’ve ensured that the hospitals have information packets to give to new parents (in English or Spanish), and we’ve encouraged them to take advantage of our welcome-basket program. We’ve given presentations to teach medical professionals how to talk to new parents about Down syndrome and to introduce them to the local and national resources available to the Down syndrome community.

Thankfully, our efforts to form relationships with the medical community in the greater Bay Area have paid off. Our director of new parent support, Nancy Ferguson, has so far received calls from 56 families this year compared to 31 in 2016. These parents have reported that they were connected to us by their doctor or other member of their medical team, showing us that indeed our outreach efforts have worked.

We look forward to continuing to build relationships with the local medical community and to welcome new families in 2018, our 20th year of service.

Ability Awareness: from page 10

in some manner. My point has always been that not only is it okay to notice and ask questions about differences, but that I want to acknowledge and celebrate those differences in a positive light. In the fifteen years that I’ve been doing ability awareness work, I’ve seen a significant shift from both parents and educators in their desire for such education. We used to have to spend time convincing folks of the benefits of such discussions; now we can’t keep up with the demand for facilitating them. This is good news! As an organization, we now have 2 additional employees who help meet the demand, one of those individuals being Eli, my 21-year-old son with Down syndrome. We’ve directly educated well over 7,000 individuals about Down syndrome, facilitating friendships and ways to be respectful and supportive peers. Because we cannot keep up with the demand for presentations, we recently created training materials to help parents and educators feel more confident in giving such presentations on their own (these are found on our website).

We’ve received letters of thanks, reports from parents and educators about the positive impact such discussions have on their students, and witnessed the “Aha, I get it and embrace it” moments in the classroom. There is no doubt we’re changing attitudes, creating positive change, and helping to grow friendships.

DOWN SYNDROME CONNECTION OF THE BAY AREA CONNECTION GROUPS



An opportunity to meet and share with those who have similar interests, seek peer support, and give back to other DSCBA families by providing guidance from your own personal experiences. Facilitators help keep the dynamics of each member’s input a helpful and meaningful experience. As a result of the connections made in these settings, many members experience lifelong friendships of support and understanding along with gaining powerful knowledge that leads to success for the child, the family, and the community at large.

Facebook Private Connections



- ★ **Parents/Caregivers of Teens and Adults with Down syndrome**
Open to all Bay Area parents and caregivers of teens and adults with Down syndrome.
www.facebook.com/groups/dscba.teensadults
- ★ **Bay Area Down Syndrome and Autism Alliance**
Open to all Bay Area parents, family members, caregivers, and others working with a child or adult who has a diagnosis of both Down syndrome and autism.
www.facebook.com/groups/dscba.autism

Group Connections



Many groups meet at scheduled times to provide connections and support in person. Most groups meet monthly at the DSCBA office in Danville, but please see our website for current dates and times. Please note: some groups may involve bringing your children. Please check the website for details.

dsconnection.org/connection-groups

- ★ **Early Connections**
Friendly and supportive environment for parents and their babies (ages 0–3) with Down syndrome where we share helpful information to support your baby’s development.
- ★ **Parents with School-Aged Children**
Parents supporting each other with knowledge and information necessary to meet the educational needs of their children: best practices, rights, and advocacy.
- ★ **Peninsula Family Support Group**
A group of Peninsula-based parents, who come together monthly to share, learn, and take part in fun activities.
- ★ **Grandparents**
Grandparents of children with Down syndrome are welcomed and encouraged to join our group to exchange information, share common experiences, and be encouraged by other grandparents with similar issues and concerns.



Down Syndrome Connection of the Bay Area
Empower - Inspire - Support

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Early Connections

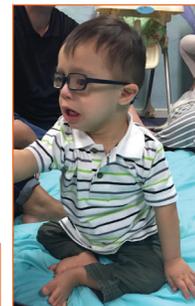
Nancy Ferguson

The DSCBA was started 20 years ago, serving a total of 60 individuals of all ages with Down syndrome. To say we have grown is an understatement! In 2017 alone, we welcomed 56 new babies and their families.

So much has changed in the last 20 years, including the way we connect and support families. In 1998, when the DSCBA began, the primary way we communicated with new families was by a landline phone call or a face-to-face meeting. Today, we still meet new and expectant parents in person, but that is only the beginning. After the initial meeting, families are invited to join us at our Early Connections support group. There they can exchange contact information with other families. Our Facebook page connects families to more than 4,300 Facebook followers. As the director of parent support, I can reach out to all of our Early Connections families via email or text if a family has a question, concern, or recommendation to share with our group.

What hasn't changed is our commitment to welcoming, supporting, connecting, and celebrating new and expectant families. Today we have the best of all worlds: meeting in person to welcome new families to the DSCBA; bringing families together in our Early Connections support groups; and connecting and communicating using technology and social media.

Early Connections, more photos on page 13



A Sweet Time at Tal's Patisserie

Marianne Iversen

Danville's adult class had the opportunity to have firsthand baking experience at Tal's Patisserie, an all-natural neighborhood bake shop in Danville. The students learned to roll out and braid Challah bread. While the bread was baking everyone learned how to use a pastry bag to decorate cupcakes. The results were amazing both in taste and beauty!

Special thanks to owner Tal Sendrovitz for showing us a great time.

Background image: Challah bread ready for baking

Below: Teresa Blakeslee rolls the dough



Left: Malia Ramsey uses the pastry bag like a pro



Above: K. Leigh Alfrey decorates a cupcake



Left: Rolling the bread dough

Below: Tal shares her expertise

Left: Happy bakers!



Right: Stacey Elliott made a beautiful flower from the icing





Musical Connections

Nicole Patton, MA, MT-BC, Neurologic Music Therapist

Making music with children and their families at the Connection is a highlight of mine. I've been involved with the Connection since the year 2000. My involvement started when I struck up a conversation with another mom at the park that sounded like me—having a Southern accent comes in handy sometimes! Her son Andrew has Down syndrome. We discussed her recent move from Atlanta and how I had done my Music Therapy internship there. The rest is history!

I've been involved in several areas of the organization over the years while also being the Music Therapist. We started off offering a Music Therapy group once a month. That group grew so large that every month we now offer two Music Therapy groups in Danville and one in Foster City.

It's such a blessing to get to observe the achievements and growth the children make from month to month. We've even had expecting moms come join the group. Babies start off in the infant through age four group and then move up to the older group. From Katy, "Will has attended Music Therapy groups since he was an infant. He still looks forward to it, and he is eight years old now. His thirteen-year-old sister loves attending as well. It's a wonderful environment where the kids can have fun with music and dancing."

The relationships that Music Therapy offers are truly unique. As we have expanded the groups, more extended family members have gotten involved. Grandparents from Sacramento drive to Oakland once a month to pick up their granddaughter and bring her to the Danville group. Both parents and siblings are often able to attend our Saturday groups. It's a wonderful sight to see the smiles on so many faces. I am truly honored to be able to share my love of music with the families of the Connection. Thank you for the opportunity. Keep on making music!



Don't Just Dream It—Plan It!

Nancy LaBelle

The steady growth of our organization is attributed to many factors: staying focused on our member's needs; being available; making outreach a priority; continuing to nurture our community partnerships; having a dedicated and passionate staff and board of directors, committed volunteers, and a very generous community who all have a desire to see us thrive.

For the past few years it was clear that we were outgrowing our Danville center space. We thought about moving, but, after researching and understanding the high cost of Bay Area real estate, moving was clearly not an option. Our focus then shifted to the question, Could it be possible to have our dream in our existing space?

Local architect and Danville Mayor Newell Arnerich donated his time and talent, and our dream began to evolve on paper. We realized we could indeed have everything we wanted by rearranging the order of rooms and using the square footage more efficiently.



Left: The office comes to life



Top left: And the walls come tumbling down
At left: Framing going up
Below left: Drywall going up



Above: Our cozy family waiting room



Left: Double the space for classroom activities



Clockwise from second-left: Stirring up friendship and fun in our brand new kitchen



Left: Plenty of room to dance

With a design in hand, we started a capital campaign, sending out a proposal to many of our faithful donors who have believed in us for many years. The proposed plan was to increase the size of our classroom with the ability to divide it into two unique rooms; to have a working kitchen where life skills could be honed and friendships are made around cooking projects; and to have two additional offices for staff,

therapists, and specialists working daily with our families.

And that is exactly what we have going into our 20th anniversary year.

Plan It! see page 15





Left: The Lending Library and beautiful color scheme



Above: A space to welcome new families



Left: An organized storage room

What started as a dream became a plan. The plan became reality because of a generous community. Words cannot express how grateful we are to the following donors:

The Joseph and Vera Long Foundation
Property Owner and 19-Year-Landlord
Mr. Baldacci

Danville Mayor and Architect Newell Arnerich
Danville Sycamore Rotary
Danville Rotary
Kiwanis Club
of San Ramon Valley

A 10 Year Reflection

Heather Vukelich, MS, SLP-CCC

This year as the 20th anniversary of the DSCBA approaches, it will also signify my 10th year working within our community. This completely blows my mind. As a longtime friend of our community, Martha Hogan, a DSCBA co-founder, helped me cultivate my love for children with DS through Challenger Baseball and DS League related activities when I was in middle school and high school. Then, in 2008, everything came full circle when Nancy LaBelle, Kathy Harkins, and Martha Hogan gave me the opportunity of a lifetime to begin my private practice inside the doors of the DSCBA. You would not believe how fast a supply room could be cleaned and turned into a therapy room! It didn't take long for me to realize that one of the significant needs in our community was Oral Placement/Feeding Therapy. It took me a couple years of intensive training to feel confident in my abilities. I am forever grateful to all of the families who learned with me!

Recently, my interest in oral development has continued to evolve to include the relationship between facial and airway development, sleep apnea, orthodontics, and speech clarity. Dr. Brian Hockel, DDS, has played an integral part in teaching and introducing me to this integrative area. Other new areas of interest include tongue and lip tie management as well as biomedical



support. Treating children more holistically has helped me to understand the role that genetics, food, supplements, and sensory-motor development play in a well-functioning, healthy child with Down syndrome. Being part of this community has fulfilled me beyond measure. It has helped me to become a better mother and empowered me to continue learning within my profession. Inclusion really works in so many beautiful ways. I am grateful to have been given the opportunity to be included in the love bubble that I like to call the DSCBA. Learning, serving, and growing with you over the past 10 years only leaves me excited to see what the next 10 years hold!



Above: Targeting jaw control for higher level speech sound development

Top left: Jocelyn began therapy drinking six bottles of formula per day. After six months of therapy she now enjoys whatever her family eats. Way to go Jocelyn!

Top right: Practicing oral placement for the /m/ sound

In the Beginning

MARTHA HOGAN

DSCBA founder and current board member



Martha Hogan with her son Blair

In January of 1998 the Down Syndrome Connection was founded by a small group of caring people. They believed that it was essential to provide supports and services to families who have babies born with Down syndrome as well as to offer classes and therapies important for the development of children, teens, and young adults. Developmental Therapist Katherine Sefton and Nancy Henderson, an adaptive PE teacher, created our Peer Development classes, formerly known as Step classes, which helped many Bay Area children reach important milestones that their families hoped for. In addition to me, the founders of the Down Syndrome Connection were Karen Balos, Katherine Sefton, Nancy Henderson, and Kim Carson.

Being a grassroots organization, we didn't have funds for office space that first year, so we turned to the Town of Danville and St. Joan of Arc Church for help. We were offered space at the Veterans Memorial Building and at the church free of charge to conduct programs. Many community members volunteered to form our first board of directors and worked very hard to raise the funds that ultimately helped the Connection open an office in Danville. Other contributors, such as Janet and Jim Richman (Attorney at Law), gave their time and talent to assist us to gain our 501C3 status.

I have fond memories of opening my home for board meetings and family support groups. The money we raised paid for teachers and supplies. At the end of the first year, we raised a total of \$82,000, which included a generous startup grant of \$50,000 from the Wayne and Gladys Valley Foundation—for 20 years this foundation has been providing program funding for our members.

It is important to never forget our beginnings. I marvel at where we started and where we are today, 20 years later. It has been a pleasure to see what we have become in such a short time! I applaud the fantastic journey of our growth. I wish there was enough space to mention all who have helped and still help all these years later! It will always take a village, hard work, passion, and sacrifice on the part of board members (which I am proud to remain part of), staff, families, and the community at large to keep this beautiful organization going forever.

My love and appreciation to everyone.

JANET RICHMAN

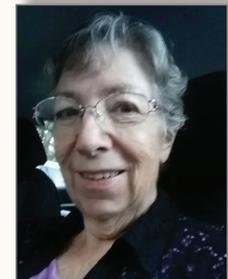
The DSCBA was like a phoenix that came out of the ashes: slowly, stumbling at times, with so many challenges, but with determination, love, and compassion that were the driving force to support families with children of all ages with Down syndrome. No one ever quit. No one ever threw up their hands and said this was too hard. And it was hard. Everyone—staff, many volunteers, the community—worked together to make the fledgling organization sustainable because the families needed this organization, and we needed to be there for them. All the hard work of 20 years ago has proven that love, hope, and compassion will win out when the intention is to serve those who need the DSCBA.



Janet Richman

KATHERINE SEFTON

The value of family support, information and training, developmental therapy, and social empowerment for folks with Down syndrome cannot be overestimated; this was proven by how quickly and completely this organization has grown. The Down Syndrome Connection started 20 years ago in tiny basement rooms with very little equipment and no money. The organization was born out of difficult and painful times. We were a dedicated group of parents and professionals who were already working together to make better the lives of people with Down syndrome and to support their families. It was unexpected that we would be looking for a new home, a new name, and a new place to work with children who have Down syndrome and with their families. It was a confusing time—sometimes frustrating. But we banded together and found spaces in which to work. We cobbled together a program out of love, energy, and skills, and put it into place quickly. Like any time of great transition, there was a combination of exhaustion and exhilaration. It was a great privilege to be there as this organization came into being. Watching as it has grown in size and breadth of program, I continue to be in awe of the work done by the folks there, to be grateful that DSCBA stands as an example of what can be done and must be done so that babies, children, and adults with developmental challenges can rise to and exceed those challenges.



Katherine Sefton

A Night to Remember

- Nancy LaBelle



Thank you to those from the community, over 100 people including many of our members, who attended the 20th anniversary ribbon cutting and open house on February 8.

Cutting the ribbon, showing off our newly renovated office, and dedicating our new kitchen to the Joseph and Vera Long Foundation, a major contributor to our remodel project, were the highlights of the evening. We were grateful to have Milton Long, executive director of the foundation, attend to accept the dedication.

Thank you to the Danville Area Chamber of Commerce, Danville Mayor Newell Arnerich, and Assemblywoman Catherine Baker for your support and recognition.

We are also grateful for the many local businesses that donated food for our guests to enjoy.

The generosity of the community is what has kept us strong for 20 years. We felt the love on this celebratory night that we will not soon forget.

THANK YOU

FOUNDATIONS, FAMILY FUNDS, CORPORATIONS, AND SERVICE ORGANIZATIONS

The Albertsons Companies Foundation –
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IN HONOR OF KATIE BUCKMAN
Erika Buckman

**IN HONOR OF AYALA DAVIDSON
BYCEL**
Marvin Loeb

**IN HONOR OF JENNIFER AND
ELI COOPER AND MATEO
CANDELARIO**
Cindy Erhart

**IN HONOR OF EMERY DELACRUZ,
A FEARLESS AND VIBRANT KID**
Robin and Art Birakos

**IN HONOR OF ADAM AND
NANCY FERGUSON**
Susan Bowman

IN HONOR OF BRANDON GARCIA
Richard Gellman

IN HONOR OF SAMUEL GLADDERY
Betty Tulley

**IN HONOR OF NICOLE HENRY
AND FAMILY**
Patricia Banks-Mgbam

**IN HONOR OF ELLEN HOVEY
A CHAMPION OF CHILDREN WITH
DOWN SYNDROME, INCLUDING HER
OWN SON, JEREMY HOVEY**
The Tre Sorelle Fund,
Elizabeth Boatwright,
Sally Jane Marsh,
Suzanne Nielson

IN HONOR OF BLAIR HOGAN
Paul and Carol Rioux
David and Victoria Smith

IN HONOR OF MARIANNE IVERSEN
Dona Taylor

**IN HONOR OF THE WORK YOU DO WITH
LULU JENSEN**
Scott and Karen Sommer

IN HONOR OF LUCAS PATERNO
Christopher Paterno

IN HONOR OF THE STAFF OF DSCBA
Janet Richman

IN HONOR OF DECLAN TYLER
Laura Kennedy

IN MEMORY OF GENE COLE
Mary and Will Gissel

IN MEMORY OF BIAGINA COVELLO
Joseph and Carolyn Covello

**IN MEMORY OF
ED AND FLORENCE SKULSKI**
Kati Skulski

ON BEHALF OF EMERY D.
Laura Delacruz

ON BEHALF OF MARGARET KELLY
Laura Lonis

**WITH APPRECIATION OF JENNIFER
COOPER AND HER SON ELI FOR
EDUCATING STUDENTS AT GRATTAN
ELEMENTARY SCHOOL IN SAN
FRANCISCO, FROM RYLAND
ALLDREDGE'S PARENTS**
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Tracy Trotter
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in memory of Kyle
Martinez, for
Christian James
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behalf of Sarah Najar
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Ravinder Khangura
Scott Lam
Isela Lopez-Garibay
Laura Martinez
Jennifer Nunez
Jenny Rios, in honor of
her daughter Bianca
Charles Seufert
Corbin Shields
Ray Szeto

THANK YOU!! see page 19

DSCBA Wins Share the Spirit Award

Tempra Board

For the last two years, DSCBA has been the proud recipient of a Share the Spirit award, among several other local nonprofits, provided by a partnership of the Contra Costa Crisis Center and the Bay Area News Group—East Bay Times. This year the award came with a \$6,000 grant towards our Expectant and New Family Program. Through this program we provide pregnant or new parents with compassionate and up-to-date information, resources, and support when confronted with a new diagnosis of Down syndrome. We also help educate the medical community who has first contact with these families.

In addition to this much-needed funding, the award facilitates news stories during the holiday season about DSCBA and the families we serve. This year, our Medical Outreach Coordinator Cathleen Small and her family, including her son Sam who has Down syndrome, were featured on the front page of the East Bay Times.

When Cathleen gave birth to her son, Sam, in 2012, she didn't know where to turn. She didn't know anything about Down syndrome or anyone who did. She searched the internet and quickly found the DSCBA. Cathleen attended her first support meeting at DSCBA when Sam was three weeks old and remembers "that was the first moment I felt that everything was going to be okay—that Down syndrome wasn't going to rule our lives."

Cathleen and Sam began attending the Early Connections support group right away and Cathleen looked forward to connecting with fellow parents each month. Now age five, Sam has completed two summers in DSCBA's Communication Readiness Program and attends weekly peer development classes at the DSCBA. The whole family goes to events such as the annual Step Up Walk and Holiday Party.

Cathleen became DSCBA's medical outreach coordinator in 2015, citing her own less than positive experience with Sam's diagnosis as part of her motivation, and learning that other parents had similar experiences. She now helps support parents and the medical community with compassion, information, and resources. "I believe so strongly in the services DSCBA offers that I want to help connect new parents with them."

Thanks to Cathleen's outreach efforts, as well as stories like the one in the East Bay Times, DSCBA welcomed a record number of babies with Down syndrome into our family. That means more children than ever before in the Bay Area have the opportunity to get the therapies they need to reach their fullest potential, and their parents get the support they need at what can often be a stressful time. DSCBA thanks the Bay Area News Group and Contra Costa Crisis Center for awarding us this funding and public relations support.



Sam,
Cathleen,
Theo, and
Chris Small

THANK YOU!: from page 18

PRICEWATERHOUSE COOPERS LLP

Anonymous

SCHOLARSHIPS

Kirsten Massa

SRV THUNDERBIRDS FUNDRAISER IN THE NAME OF SHILOH LEONARD

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WELLS FARGO

Lisa Chen

YOUTHBRIDGE COMMUNITY FOUNDATION

Anonymous

Please know we work very hard to ensure your kindness is acknowledged. If your contribution to our success was received after the newsletter went to press, we will be honored to highlight your generosity in the next edition. Thank you!

VOLUNTEERS

DEDICATED CLASSROOM VOLUNTEERS

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Tori Emanuel
Dawn Handley
Brytney Lee
Ben Park
Joey Powada
Kathleen Stein
Gracie Sula
Toni Sweet
Gabby Testa
Alex Wai
Vivian Yao

Let's
Celebrate!

See you at the GALA
on Saturday, April 14!

See page 7 for details

Making the Connection

Volume 11 No. 1 - March 2018



Down Syndrome Connection
of the Bay Area

www.dsconnection.org • Phone 925-362-8660
101 J Town & Country Drive Danville, CA 94526

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Our Mission

To empower, inspire, and support people with Down syndrome,
their families and the community that serves them,
while fostering awareness and acceptance in all areas of life.

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The winner is . . .



The DSCBA proudly accepted the
**2017 Charitable Organization
of the Year**
award from the Danville Area
Chamber of Commerce
at the State of the Town event
on March 15, 2018.

***Thank you to all who
nominated us!***

DSCBA 2018 Upcoming Events



April 14, Saturday: *See details on page 7*

20TH ANNIVERSARY GALA!

July 4, Wednesday: *More details online*

4TH OF JULY PARADE

October 7, Sunday: *More details online*

STEP UP FOR DOWN SYNDROME WALK AND FAMILY PICNIC

December 2, Sunday: *More details online*

HOLIDAY PARTY