

# *Our Story and 2019 Year in Review*

The Down Syndrome Association of Orange County (DSAOC) had another busy and meaningful year.

Besides our regularly scheduled weekly, monthly and annual programs and activities, DSAOC had a great year of events, outreach, Down syndrome awareness, advocacy, collaborations, parent support and more.

Enjoy our 'Year in Review', and be sure to check out DSAOC Videos on our Community Corner page and YouTube:

Community Corner:

<https://www.dsaoc.org/community-corner.html>

YouTube:

[https://www.youtube.com/channel/UCGDW3KzhDd\\_xK4eTWE1CITA](https://www.youtube.com/channel/UCGDW3KzhDd_xK4eTWE1CITA)



Please consider a Year-End Gift to DSAOC. Your donation is tax-deductible and will go a long way to support our upcoming year.

<https://give.classy.org/DSAOCDONATION>

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DOWN SYNDROME ASSOCIATION  
OF ORANGE COUNTY

CHANGING PERCEPTIONS - CHANGING LIVES

# *Our Story*

*DSAOC was founded by the true pioneers of Down syndrome support and awareness in Orange County.*

**In the 1970's**, a group of parents in Orange County were able to connect with one another after they had given birth to babies with Down syndrome. Although they were given a grim outlook about their child's futures, they decided to take their babies home, introduce them to their family and friends, integrate them into their community.... and LOVE them.

Realizing the lack of resources and support available to them when their babies were born, they began gathering as much information as possible and letting local labor & delivery hospitals know that they were available to provide support to any family who had a baby with Down syndrome. Carrying around a filing box that contained family contact information as a make-shift database, this small group of parents pulled together resources, and in 1978 applied for non-profit status for P.R.O.U.D. (Parents Regional Outreach for Understanding Down Syndrome). By 1980, P.R.O.U.D. had a Board of Directors and was officially functioning as a 501 c 3 non-profit, serving families throughout greater Orange County.



## Did you Know?

DSAOC is the pioneer of  
Hospital Outreach and  
Prenatal Diagnosis Support.

*The Founders of P.R.O.U.D. (DSAOC) began reaching out to hospitals in the 70's, building professional relationships with Social Workers so they could work together to support new parents who had a baby with Down syndrome.*

*In the 1990's when prenatal diagnosis was becoming more common, P.R.O.U.D. (DSAOC) supported parent, Linda Chan Rapp, with the creation and dissemination of "The Light at the End of the Tunnel", an informational and inspirational booklet that DSAOC mailed across the U.S., Canada and to other parts of the world. <https://www.ndscenter.org/wp-content/uploads/Light-Tunnel-all-LR.pdf>*

Primarily working out of family's homes and having board meetings at kitchen tables, P.R.O.U.D. found itself growing in numbers and funding in the late 90's, allowing the acquisition of a small office in Santa Ana. In the year 2000, the organization hired its first Executive Director. Then, in early 2004 came the new organization name, from P.R.O.U.D. to DSAOC - Down Syndrome Association of Orange County.

Continuing to grow with support from families and the community, and outgrowing the small office in Santa Ana, DSAOC was fortunate to gain grant support to find a new location. In October 2005, DSAOC opened its doors to the 3,000 square foot Center in Costa Mesa where it is currently located. The DSAOC Center houses an expanding resource library, a lounge area, a board room, and an activity center where a wide range of activities and support groups are held. The organization, which previously focused most of its support on families who had children with Down syndrome between the ages of 0 and 5, has now grown to provide programs, services, resources and activities for all age groups, and has programs for the entire family, including siblings. Currently serving more than 2,000 families in Orange County and surrounding areas, DSAOC also assists educators, health care professionals, researchers and therapists with information, training and support materials. The organization also provides students with volunteer and intern opportunities, helping them gain valuable social and leadership skills. Affiliated with the National Down Syndrome Society (NDSS) and National Down Syndrome Congress (NDSC), DSAOC is the only county wide organization dedicated solely to serving Orange County's Down syndrome population and their families throughout their life journey.



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## ***Did you Know?***

*DSAOC and CHOC Children's just celebrated 10yrs of partnering on the CHOC Children's Down Syndrome Clinic.*

*DSAOC recently recognized our long-standing alliance with CHOC Children's during the 2019 OC Buddy Walk with a special award celebrating the 10-year anniversary of serving hundreds of children annually at the CHOC Children's Down Syndrome Clinic.*

## **Focus on Wellness:**

DSAOC works hard to provide programs, services and opportunities for individuals with Down syndrome to reach their full potential. From the beginning, by supporting the parents and helping them navigate and advocate for the appropriate services and early intervention therapies, to providing supplemental therapies at the center, providing support groups, luncheons, Sibshops, and other ways for parents, grandparents, siblings and caregivers to connect, and finally by offering weekly and monthly programs for teens and adults with Down syndrome that focus on 3 major areas; social skills, mental wellness and physical wellness. DSAOC is committed to supporting the overall wellness of the entire family and caregiving circle.

Due to the myriad of healthcare issues that can affect individuals with Down syndrome and cause obstacles to reaching their full potential, DSAOC created alliances with CHOC Children's and UCI Healthcare to bring both a Pediatric Clinic and Adult Clinic to our families. The CHOC Children's Down Syndrome Clinic opened in late 2009 and the UCI Adult Down Syndrome Clinic opened in March of 2006. DSAOC also collaborates with UCI's Down Syndrome Program and Alzheimer's OC on research opportunities and research updates on the connection between Down syndrome and Alzheimer's Disease. DSAOC also co-hosts support and informational meetings for those affected by, or that have an interest in, the Down syndrome/Alzheimer's connection.



## Parent Support Programs

DSAOC support groups, mentor programs, Dads group and seminars/workshops supported more than **170** families in 2019.

### Families that Relocate to Orange County

DSAOC's Parent Support Program not only supports our new and expectant parents, it also supports families who relocate to Orange County from other counties, states or countries. We support these families by connecting them other families in the area they are moving, and we help provide information on school and supplemental education options, local therapy and healthcare, and make sure they are connected to the Regional Center and other local service organizations.



**Circle of Friends Support & Networking Group** Monthly Support Group for Expectant and New Families who have a child with Down syndrome age 0-5yrs.

DSAOC met and supported **47** new families this year! It is always such a pleasure getting to know our families and providing meaningful support to help them navigate the first few years of their child's life and provide them with resources for their loved one's life journey so they can reach their full potential.

In 2019 DSAOC hosted **11** monthly support and networking groups, pulling in experts and resources from our community to provide educational presentations to our new and expectant families. We also had a lovely holiday celebration and open forum. This group meets in both English and Spanish.

### Prenatal Support

Expectant parents have non-invasive prenatal testing available to them that can check specifically for the genetic material that would indicate a Down syndrome diagnosis. Due to these less invasive tests, DSAOC receives an increased number of prenatal diagnosis referrals. This year, DSAOC supported **7** expectant parents by providing them with the inspirational booklet, "Light at the End of the Tunnel", as well as other informational booklets and a parent mentor that also had a prenatal diagnosis.



### DSAOC Parent Mentor Program

DSAOC trains new parent mentors and offers refresher training for current mentors to make sure everyone is up to date on the most recent resources and information pertaining to our community. In September of this year, we trained **10** new Parent Mentors that have already been assigned to new families. Our Parent Mentors help our new families navigate this unplanned journey and can share about their own experiences.



**Annual New Parent Luncheon** For expectant and new parents who have a child with Down syndrome age 0-5yrs.

DSAOC's free annual New Parent Luncheon had just over **80** people in attendance. The food, beverages and social time were wonderful, and we had a lovely view overlooking the harbor. Thank you to our amazing friends at the Seal Beach Yacht Club for being our bar and venue host.



**DSAOC Supports families who are helping to create more Down syndrome awareness**

This year we hosted a Book Signing Event to highlight some of our families who have chosen to spread awareness and messages of inclusion by writing books. These are just a few of the amazing authors that are in our community.



- ✦ Heather Avis: Author of "The Lucky Few" & "Scoot Over and Make Some Room: Creating a Space Where Everyone Belongs"
- ✦ Michelle Tetschner: Co-Author of "FULLY INCLUDED – Stories to Inspire Inclusion"
- ✦ Sandra McElwee: Author of "Who's the Slow Learner? A Chronicle of Inclusion and Exclusion" & "Who's the Slow Learner? Adventures in Independence"
- ✦ Clara Kim Lee: Author of "The Maker"



**DSAOC Dads Group**

We have a special support and networking group just for our Dads that is facilitated by one of our DSAOC Dads. This year, besides meeting up to chat and also joining us to volunteer for a couple of our events, some of our DSAOC Dads got together for a bonding experience at an escape room, funded by our sock fundraiser we had earlier in the year. We look forward to getting this wonderful group of Dads together again in 2020.





## Annual Educator of the Year Recognition & Award Program

DSAOC was honored to once again recognize Educators in our community that are making a positive difference in the lives of individuals with Down syndrome and getting them on a path to reaching their full potential. This year DSAOC recognized Julie Demuth, Michelle Kelly and Rosemary Lotts from the Los Alamitos USD Adult Transition Program.

### DSAOC Sibling Programs

Bi-Monthly Sibshops program for siblings age 7-14yrs who have a brother or sister with Down syndrome

*Sibshops was tons of fun this year! We supported more than 30 siblings, and a few of the older siblings are set to volunteer with us in 2020 so they can support the new siblings joining the program.*

### Resource Fairs, Outreach and Community Events

*DSAOC had a busy year participating in 34 outreach and resource fairs, as well as community events, which allowed us the opportunity to create more awareness about Down syndrome and DSAOC and talk about the needs within our community.*



### DSAOC Supports Students through our Comprehensive Intern and Volunteer Programs

*This year DSAOC supported 15 Students who needed intern opportunities for their college course requirements. We also provided non-profit, disability awareness and office experience to 5 high school students who were working on projects and wanted the experience. We signed off on more than 5,000 service hours in 2019 for several of our amazing volunteers!*



## Homeschool Group

DSAOC had another busy year providing support, coordination of the activities, and being the meeting venue for our weekly Homeschool Group. We also coordinated the social skills therapy program with Chapman University for an important speech therapy program that is part of the curriculum for the kids in the Homeschool program. We supported **9** families and their children each week in this year's Homeschool and Speech Therapy program.

## In-Center Therapy

This year we started another social skills speech therapy program with Chapman University's Communication Sciences and Disorders grad students that is for children with Down syndrome age 18 months to 4 years old. This program supported **6** children each week and a new session is starting in January 2020.



## Mano a Mano Early Literacy Program

DSAOC continues to support our Spanish language community by offering support groups, presentations in Spanish, and providing a monthly early literacy program for children with Down syndrome age 4-16 that are growing up in primarily Spanish language homes. Through this program, using Terry Brown's So Happy to Learn curriculum, our teachers and volunteers reinforce the English language and help the children develop a love for staying focused and learning. This program also educates and supports the parents so they can be more engaged with their child's learning. This program supported just over **40** families this year.



## Music & Movement



## ROMANCE AND SEXUALITY IN INDIVIDUALS WITH DOWN SYNDROME

Master's Thesis | UC Irvine

Brief Survey:

- Marshall B. Ketchum University, PA Studies
- UCI, Div. of Genetic and Genomic Medicine
- Stanbridge University, Occupational Therapy
- OC School of the Arts, School of Dance

## DSAOC Supports University Students with their Capstone Projects, Master's Thesis, and OC School of the Arts dance presentation

DSAOC not only supports our families, we feel it's important to support youth and young adults who want to learn more about our population and are working on projects to further their understanding, knowledge and help them achieve their educational goals. We were thrilled to support Master's Thesis projects, Capstone Projects and help a student coordinate a dance event and fundraiser for DSAOC.



**Community Collaborations, bringing even more opportunities to our families** Each year DSAOC Collaborates with several groups to bring more educational and recreational opportunities to our families. Below are just some of the many groups we collaborate with:

- UCP-OC – Orange County Bike Camp
- RAD Camp and Rosary Academy - Annual Teen/Adult Dance
- Alzheimer's OC, UCI Mind and RCOC – Annual 'Ask the Doc' Seminar
- Orange Elks – Annual Adult Mixer and Summer Picnic
- Pujols Family Foundation – Annual Teen/Adult Prom
- Garden Grove Elks Lodge – Annual Trick or Trunk and Breakfast with Santa
- Seal Beach Yacht Club – Annual New Parent Luncheon
- National Charity League-Pacific Coast Chapter – “Welcome Baby Baskets” and our annual Family Activities
- UCI Department of Pediatrics, Division of Genetic and Genomic Medicine – Annual tour for the Genetics Counseling Students that includes a Q&A and a meet & greet with our teens and adults in a non-clinical setting.
- Mater Dei – Annual Jr. Dance and Boo Bash Costume Party and Dance



**THE JR. DANCE**



**Teen/Adult Programs** DSAOC's Teen/Adult Programs focus on 3 main objectives; Social Skills, Mental Wellness and Physical Wellness. Our Teen/Adult programs run weekly, monthly and as annual events.

*Weekly and Monthly Programs support approximately 50 teens and adults with Down syndrome and our Annual Teen/Adult Programs include more than 300 individuals.*

- Ballroom Dance/Hip-Hop
- Book Clubs
- Drama Therapy with Alexis
- Fitness & Nutrition
- Yoga with Julie
- Taekwondo with Jonathan and Amisha
- Art for the Soul with Vicky
- Vocal Class with Beth
- Karaoke Fun
- Monthly Teen/Adult Bowling League
- Annual Social Mixers
- Annual Red Carpet Ball Dinner & Dance



**Summer Programs** Each year in June, July and August, we bring special Summer Programs to the DSAOC Center for all ages. In 2019 we offered the following programs and had just over 30 children, teens and adults that came each week to share their summer with us.

*Summer Programs this year included:*

- Fitness & Nutrition
- Soccer Drills & Skills
- Art Class with Vicky
- Basketball Drills & Skills
- Vocal Program with Beth
- Photography Class
- Signing Time with Annie
- Music & Movement



**Annual Family Activities** DSAOC has 3 Annual Family Activities - Summer Picnic, Fall Trick or Trunk and Breakfast with Santa.

*Our Family Activities provide a great way for families to connect in a fun, informal manner. These activities are usually free, or with a suggested donation to help cover expenses. Unless there are venue space restrictions, our family activities are for immediate and extended family and caregivers. This year our family activities each had more than 200 people in attendance.*



**Community Events** Each year we work hard to find opportunities to get out into our community and have events in public to help create more awareness about Down syndrome and DSAOC programs and services.

*This year we took part in 8 public events (not including resource fairs and other outreach fairs) and are highlighting 4 below:*

- **World Down Syndrome Day Celebration at Pacific City, Huntington Beach**
  - Held each year on 3/21, this DSAOC event has grown in popularity and had more than **250** attendees this year
- **National Day of Service, CWS Corporate Housing**
  - A small group of our adults came together with an employee of CWS Corp Housing and supported a National Day of Service by putting together goodies for troops over seas.
- **Turnover Movie Screening, The Art Theater of Long Beach**
  - DSAOC had an opportunity to help promote this independent, award winning film because it was a family film and includes 2 actors with Down syndrome. We had just over **100** people in attendance at the movie screening that was open to the public.
- **EB Bradley Golf Event, Black Gold Golf Club, Yorba Linda**
  - We were thrilled to be invited to this event and hosted a table on the golf course that had fun games and prizes. We were also able to provide Down syndrome awareness information and ended up receiving more than \$5,000 in donations!

**Annual Fundraisers** DSAOC has 2 large fundraising events each year, and smaller fundraisers throughout the year. With a budget of just over \$400,000 needed to bring meaningful programs, resources and services to our families as well as maintain our Center, every dollar counts. Thank you for your support!

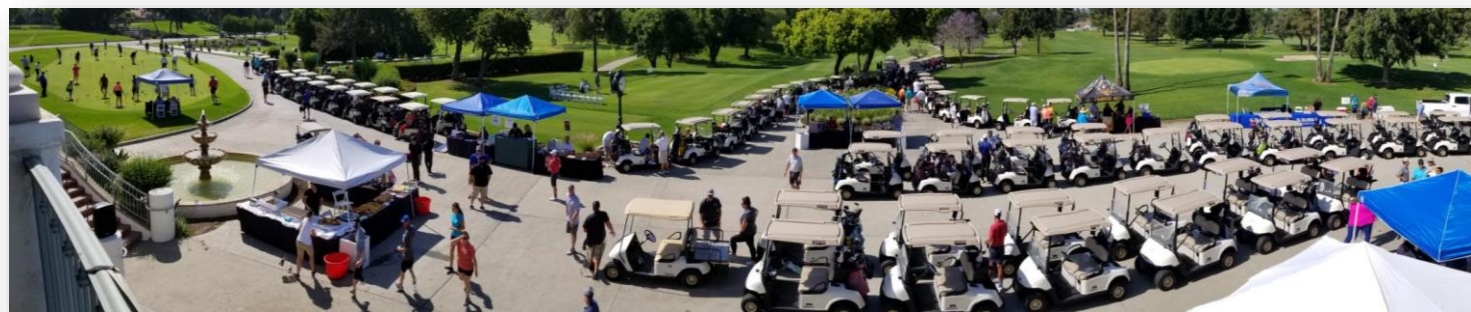
- **Orange County Buddy Walk:** DSAOC's largest annual awareness and fundraiser that takes place the last Sunday of October at the Angel Stadium of Anaheim. This year we had just over **2,200** people in attendance and had **43** exhibitors and **12** special guests.
- **Golf Tournament, Banquet & Auction:** This is DSAOC's second largest annual fundraiser that takes place the second Monday of June. This is a growing event, and this year we had **218** golfers, **25** volunteers and a total of **270** for our after-golf banquet.
- **Empowering Possibilities:** This is a collaborative fundraiser with 7-9 other similar organizations in Orange County. This fundraiser is hosted by the Orange County Community Foundation and takes place for our group in May.
- **Designer Purse Bingo:** This is a new fundraiser, and due to it's success and popularity, we are bringing it back in 2020. This year we had just over **50** people register, and everyone had a blast!
- **Giving Tuesday:** DSAOC started participating in Giving Tuesday a few years ago and we have been so moved by the generosity of our families.
- **End of Year Review and Giving Request:** This is it... this is our Year in Review and end-of-year giving request. We hope you will read all that we do and realize your contribution is going far and truly making a difference... one that you can see and feel. Come and visit us - Thank you in advance.






**EMPOWERING**  
**POSSIBILITIES**  
A GIVING DAY FOR DC NEIGHBORS WITH DISABILITIES

24 HOURS.  
8 ORGANIZATIONS.  
1 CAUSE. **MAY 30.**



To make your 2019 tax-deductible contribution to DSAOC, please visit: <https://give.classy.org/DSAOCDONATION>

# THANK YOU

**We need your support in 2020!**

Please consider an END-OF-YEAR tax-deductible Gift to support the meaningful programs & services provided by DSAOC to our community.

Thank you, sincerely.

*To make your tax-deductible contribution to please visit:*

<https://give.classy.org/DSAOCDONATION>

*For more information on DSAOC, please visit our website at [www.dsaoc.org](http://www.dsaoc.org)*

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The Down Syndrome Association  
of Orange County is extremely grateful to our  
Corporate, Foundation, and Individual Sponsors  
and Donors, as well as our Collaboration Partners,  
Volunteers and Interns.

We look forward to recognizing  
your continued support and participation.

***THANK YOU!***