NEW PARENT RESOURCES
This New Parent Resources Packet is brought to you by the Silicon Valley Down Syndrome Network and is intended to help new or expectant parents learn more about Down syndrome and provide accurate and up to date information about having a baby with Down syndrome. Receiving a diagnosis that your baby will have Down syndrome can be overwhelming. We invite you to contact our organization so we may offer support.

To connect online with families in your child’s age group, visit our organization page (svdsn.org) and become member (Join Us), then go to ‘Baby to Toddler’ Forum (found on menu ‘Forums’ after you log in).

To join the online discussion forum for the DS community in Bay Area, visit svDSnet Discussion Group. (https://groups.io/g/svDSnet).

For more interaction with fellow families, visit the Silicon Valley Down Syndrome Network (SVDSN) on Facebook (https://www.facebook.com/groups/svdsn/) and send a request to join.

If you would like to meet the fellow parent who also has a child with Down syndrome, please contact the SVDSN Family Support Coordinator Liz Bongiorno at 408-673-0775 or svdsnwelcome@gmail.com.
Silicon Valley Down Syndrome Network (SVDSN)

SVDSN is a network of families with children born with Down syndrome. We come from all walks of life, and our common goal is to provide a community of support for individuals with Down syndrome and their families.

SVDSN is a program of the Valley Medical Center Foundation, a 501(c)3 non-profit organization.

SVDSN c/o VMC Foundation
2400 Clove Drive, San Jose CA 95128
SVDSN main contact # 650-690-2321
info@svdsn.org,
SVDSN Family Support Coordinator – Liz Bongiorno 408-673-0775
svdsnwelcome@gmail.com
www.svdsn.org
DOWN SYNDROME CONNECTION OF BAY AREA (DSBCA) (https://www.dsconnection.org/)

Nonprofit organization with an office in Danville and satellite program locations throughout the greater Bay Area, including the Peninsula. DSCBA’s mission is 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. DSCBA provides education support for families, classes and programs for people with Down syndrome from infancy through adulthood, an Alternative and Augmentative Communication (AAC) and print lending library, support groups, special events, and more.

**DSCBA’s main office is located at:**

**101-J Town and Country Drive**

**Danville, CA 94526**

**925.362.8660**

[dsconnection.org](https://www.dsconnection.org/)

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**Parents Helping Parents**

Parents Helping Parents supports, educates, and inspires families and the community to build bright futures for youth and adults with special needs. The office has a library, and you can also access their e-library at their website.

**1400 Parkmoor Ave, Ste 100, San Jose CA 95126**

**408-727-5775** [info@php.com](mailto:info@php.com)

[https://www.php.com/](https://www.php.com/)
Center for Down Syndrome at Lucile Packard Children’s Hospital

Location – Mary L. Johnson Specialty Services  730 Welch Road, 2nd Floor Palo Alto, CA 94304
Phone: (650) 723-6858 x 1, Fax: (650) 498-4555

Service Overview
The Center for Down Syndrome at Stanford Children’s Health helps each child with Down syndrome reach his or her full potential and function as independently as possible in all aspects of school and family life. Stanford Children's is one of the few children’s hospitals in the nation to offer these much-needed services to children.

Patient care
The Center for Down Syndrome is directed by Melanie Manning, MD. She is a Clinical Associate Professor of Pediatrics and Pathology in the Divisions of Medical Genetics and Cytogenetics at Stanford and Lucile Packard Children’s Hospital Stanford. Dr. Manning is a pediatrician and clinical geneticist. She has years of experience in the care and evaluation of children with disabilities. She has particular interest and expertise in children and adults with chromosome abnormalities.

Our team of specialists includes:
- Clinical geneticists
- Genetic counselors
- Physical therapists
- Occupational therapists
- Speech-language pathologists
- Clinical nutritionists

We focus on the prevention and early detection of the medical and developmental issues associated with Down syndrome. The staff will work with each child’s primary care physician to provide the coordination necessary for the many services these children need, educate parents so that they can become strong advocates for their children and assist them to locate resources in their community.

Our services
Each patient will receive the following services:
- Comprehensive medical and genetics evaluation
- Comprehensive developmental evaluation
- Referrals as required to other sub-specialists and ancillary services
- Coordinated care for each patient managed by our staff
- Regular and/or continuing follow-up care (to be assessed and coordinated with primary care physicians and families based on individual needs)
Charlie's Clinic (aka Down Syndrome Clinic)
Location: Primary Care Clinic, 5220 Claremont Ave, Oakland, CA 94618

The Down Syndrome Clinic at UCSF Benioff Children’s Hospital in Oakland offers comprehensive, multidisciplinary visits aimed at gathering a “whole picture” of your child.

Each visit with Dr. Noemi Spinazzi, a physician experienced in the care of children with Down syndrome, includes a thorough review of the child’s medical history, with a focus on the American Academy of Pediatrics guidelines.

The visit also focuses on development, educational progress, behavioral concerns, and independence with activities of daily living. Marybeth Finch, an infant developmental specialist, works with our younger children as part of the visit, and advocates for services through the school districts and Regional Centers. Every child is screened for a dual diagnosis of DS-ASD (Down syndrome –Autism Spectrum), and formal assessments are recommended if deemed necessary.

Families are encouraged to bring the child’s individualized educational plan (IEP) and/or individualized family support plan (IFSP) for review. Advocacy around IEPs is offered to families as indicated.

The visit also includes a review of the child’s social health and socialization opportunities. Our social worker, Leticia Gomez, meets with families in person or over the phone to provide support and connect each family with community resources. The clinic organizes social events for all patients to attend, to promote the development of a supportive and inclusive community.

To be seen at the clinic:

- Ask your pediatrician to refer your child to the Down syndrome clinic at UCSF Benioff Children’s Hospital Oakland
- Call our care coordinator Miriam Castillo at 510-428-3885 ext 7887. If you leave a message, please include your child’s name, date of birth, insurance type, primary care doctor, when you requested the referral, and a call back number.
San Andreas Regional Center

San Andreas Regional Center is a community-based, private nonprofit corporation funded by the State of California to serve people with developmental disabilities as required by the Lanterman Developmental Disabilities Act. The Lanterman Act is part of California law that sets out the rights and responsibilities of persons with developmental disabilities. San Andreas is one of 21 regional centers throughout California serving individuals and their families who reside within Monterey, San Benito, Santa Clara, and Santa Cruz Counties.

Santa Clara And San Benito County
6203 San Ignacio Avenue, Suite 200, San Jose, CA 95119 Tel (408) 374-9960 Fax (408) 281–6960

Santa Cruz County
1110 Main Street Watsonville, CA 95076 Tel -(831) 900 - 3737 Fax -(831) 728 - 5514

Monterey County
1370 South Main Street Salinas, CA 93901-2727 Tel -(831) 900 - 3636 Fax -(831) 424 - 3007

Regional Center of the East Bay

The Regional Center of the East Bay [RCEB] is one of 21 Regional Centers that is a community based, private non-profit corporation under contract with the California Department of Developmental Services. RCEB works in partnership with many individuals and agencies to plan and coordinate services and supports for people with developmental disabilities, family members and community leaders in the Alameda and Contra Costa counties.

RCEB/San Leandro
Creekside Plaza 500 Davis Street, Suite 100
San Leandro, CA 94577
Phone: (510) 618-6100
Fax: (510) 678-4100
Intake Under 3 Referral Line: (510) 618-6195,  Over 3 Intake Referral Line: (510) 618-6122

RCEB/Concord
1320 Willow Pass Road, Suite 300
Concord, CA 94520
Phone: (925) 691-2300
Fax: (925) 674-8001
Golden Gate Regional Center serves individuals and families in Marin, San Francisco and San Mateo counties.

**San Francisco County (Main Office)**
1355 Market Street  
Suite 220  
San Francisco, CA 94103  
Phone: (415) 546-9222  
General Fax: (415) 546-9203  
Accounting Unit Fax: (415) 546-9233

**Marin County**
4000 Civic Center Drive  
Suite 310  
San Rafael, CA 94903  
Phone: (415) 446-3000  
Fax: (415) 446-3001

**San Mateo County**
3130 La Selva Street  
Suite 202  
San Mateo, CA 94403  
Phone: (650) 574-9232  
General Fax: (650) 345-2361  
Early Start Unit Fax: (650) 522-8901
NATIONAL INFORMATION RESOURCES

Down Syndrome Diagnosis Network
Parents from all over the United States and around the world who each have a child with Trisomy 21 (Down syndrome) and a great desire to ensure families who receive a Down syndrome diagnosis are receiving current information and support. Members come from varying political and religious beliefs with a shared vision that all families would have unbiased, family-centered diagnosis experiences with up-to-date information and access to support and connections.
612.460.0765
info@dsdiagnosisnetwork.org
www.dsdiagnosisnetwork.org

National Center for Prenatal and Postnatal Down Syndrome Resources
Providing important resources and information for new and expectant parents learning about a diagnosis of Down syndrome.
downs syndromediagnosis.org
www.lettercase.org

National Down Syndrome Congress
The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome. Their purpose is to create a national climate where all people will recognize and embrace the value and dignity of people with Down syndrome. They promote availability and accessibility to a full range of opportunities and/or resources that meet individual and family needs.
800.232.NDSC (6372)
info@ndsccenter.org
www.ndsccenter.org

National Down Syndrome Society
NDSS has worked since 1979 to benefit people with Down syndrome and their families through national leadership in education, research, and advocacy. Their mission is to be the national advocate for the value, acceptance and inclusion of people with Down syndrome.
800.221.4602
info@ndss.org
www.ndss.org

National Society of Genetic Counselors
Parents can learn more from geneticists, genetic counselors or other health care providers who can offer information about testing options and results, the accuracy and limitations of different prenatal screens and tests, recurrence chances for future pregnancies, the genetics of Down syndrome, and local resources.
www.nsgc.org

The Arc of the United States (National Office)
For people with intellectual and developmental disabilities. Promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.
202.534.3700
800.433.5255
www.thearc.org
Down Syndrome Pregnancy
A program administered by the National Center for Prenatal and Postnatal Resources at the University of Kentucky’s Human Development Institute. This program provides honest, compassionate, medically-reviewed, and informative support for those preparing for the birth of a baby with Down syndrome.
www.downsyndromepregnancy.org

Global Down Syndrome Foundation
Dedicated to significantly improving the lives of people with Down syndrome through research, medical care, education and advocacy.
www.globaldownsyndrome.org