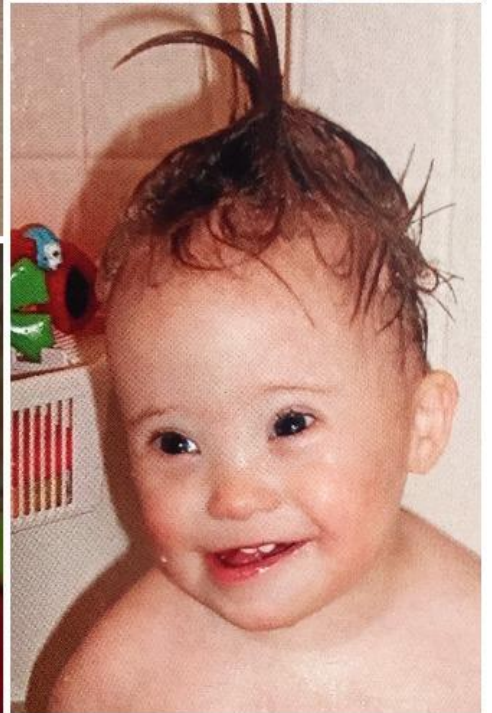


NEW PARENT RESOURCES







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 'First Connect (0 to 1 years)' 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). (<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



OTHER FAMILY SUPPORT GROUPS & RESOURCES THROUGHOUT BAY AREA

Down Syndrome Connection of Bay Area (DSCBA) (<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/)

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-Learning Library at their website. The PHP E-Learning Library includes videos, podcasts, and e-packets on a wide variety of topics to help families caring for a loved one with special needs. They are assembled in one place to make it easier to find the resources you need. PHP's staff receive calls from families with children from infancy through their child's adulthood into their 50's and 60's.

1400 Parkmoor Ave, Ste 100, San Jose CA 95126

408-727-5775 info@php.com

<https://www.php.com/>

MEDICAL CLINICS



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)

MEDICAL CLINICS – continued

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.

REGIONAL CENTERS



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

REGIONAL CENTERS – continued



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.

downsyndromediagnosis.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@ndscenter.org

www.ndscenter.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

