



Parent Guide

Updated Summer 2008

Improving knowledge for those affected by Down syndrome



INTRODUCTION

WELCOME

Introduction Letter

DSIA Fact Sheet

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Dear Parents,

It is never easy to learn that your child has Down syndrome. The news fills most parents with an array of emotions, questions and fears. The best we can do, as parents who have shared this experience, is to encourage you to learn all you can about Down syndrome, and to welcome, value and love your baby so that you can embrace hope for a bright future.

The outlook for children with Down syndrome has improved dramatically over the past several years with leaps in medical technology, improved and more comprehensive therapeutic interventions at an earlier age, and expanded educational and employment opportunities. As parents we are continually filled with hope and proof that our children will live healthy, productive and fulfilling lives.

The purpose of this guide is to provide parents of children with Down syndrome with information and resources to help with some of the challenges you may face. Parents who have shared your experience have worked diligently to include practical and useful information covering a variety of topics:

- **Heart to Heart** – A collection of experiences
- **What is Down syndrome** – General and scientific facts you can use
- **Medical Care** – Tailored medical guidelines, growth charts and access to insurance and care
- **Therapeutic Care** – An overview of therapies to help your child’s development
- **Feeding & Nutrition** – Resources for the first few months and years
- **Resources** – Community, regional, state and federal services, Web sites & publication guide
- **Organization** – File management, sample forms and long-term planning
- **Glossary** – A list of relevant terms

At first glance this guide may seem overwhelming, but you may find different information useful to you as your child grows. If you would like additional support, information or the opportunity to talk to another parent, we are available seven days a week. Please call us anytime at (916) 658-1686 or visit our Web site at www.downsyndromeinfo.org.

Best Wishes,

Elaine Linn
Executive Director

The Down Syndrome Information Alliance was formed by a network of parents of children with Down syndrome. The DSIA is a community organization dedicated to improving access to the most advanced and innovative care to promote health, education and independence. We provide resources and support to families, therapists, physicians, educators and others affected by Down syndrome in Northern California.

Inclusion of information in this resource guide does not signify the endorsement or recommendation of any agency, service resource or information.

The DSIA and its representatives are not responsible for actions taken as a result of using this guide.



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Down Syndrome Information Alliance (DSIA) Fact Sheet

Mission: The Down Syndrome Information Alliance is committed to providing resources and support for those affected by Down syndrome while ensuring access to services, treatments and programs that enhance health, quality of life and productivity.

Vision: We envision a society where those affected by Down syndrome are empowered to access the most advanced and innovative care to promote health and independence.

Purpose: The DSIA is Northern California's community organization dedicated to providing advocacy, education, social opportunities and support to children with Down syndrome and the families, therapists, physicians, educators and other professionals serving them.

Service: The DSIA serves hundreds with Down syndrome, their families and professionals in Northern California.

Activities: Family education and support

- Educational and social activities for children with Down syndrome and their typical peers, to foster learning, friendship and acceptance
- Peer mentor program for families affected by Down syndrome
- Collaboration with local hospitals to provide new parents a comprehensive "New Parent Guide"
- Scholarships to the National Down Syndrome Congress annual convention
- Distribution of "Whispers of Hope," a DSIA publication featuring local families and their experiences
- Community Network meetings throughout the area (Sacramento, Folsom, Yolo, Placer, Elk Grove)

Provider/professional outreach and support

- Outreach and ongoing communications with local professionals and providers of medical, therapeutic, social emotional and educational services to foster greater understanding and remove barriers to services
- Collaborate with professionals to provide educational advancement opportunities, including guest speakers, published materials and scholarships

Blended educational forums: Knowledge Network

- Conduct regular and period educational forums in coordination with partner organizations

Community awareness

- Host social gatherings for children and their families to foster connections and interaction with typical peers and the community at large
- Provide entertaining motivational speakers and performers for children with Down syndrome and their typical peers

Advocacy

- Network and collaborate with peer organizations to improve the quality of life in people with Down syndrome.

The Down Syndrome Information Alliance is a 501c3, non-profit organization registered with the State of California. Our Tax ID number is: 20-1702399.

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