

NEW PARENT RESOURCES



MEDICAL OUTREACH





New Parent Resources is brought to you by **Down Syndrome Association for Families of Nebraska Medical Outreach** and is intended to help new or expectant parents learn more about the condition and provide accurate and up to date information about their baby's future. 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.

For more interaction with fellow families, visit the the **Down Syndrome Association for Families (DSAF) of Nebraska closed group** on Facebook (<https://www.facebook.com/groups/dsafnebraska/>) and send a request to join. Access provides a private forum in which you may ask questions, post joys and concerns (and, photos!), or simply follow discussion threads for information, resources, advice and support.

If you would like to meet a fellow parent who also has a child with Down syndrome, we encourage you to contact Holly at **402.601.2498** or medicaloutreach@dsafnebraska.org.





Down Syndrome Association for Families* (DSAF)

DSAF recognizes that every person with Down syndrome is an individual who has a unique purpose and set of abilities. It is our mission to provide support and a positive vision for the future for individuals with Down syndrome, their families, friends, educators, and professionals who share in their lives. We are a Lincoln-based non-profit, striving to serve the Down syndrome community statewide for more than 20 years.



P.O. Box 57362

Lincoln, Nebraska

68505-7362

main: 402.421.1338

info@dsafnebraska.org

Holly, Medical Outreach: 402.601.2498

medicaloutreach@dsafnebraska.org

www.dsafnebraska.org

**Information about Down syndrome is available in
multiple languages at
www.understandingdownsyndrome.org**

OTHER FAMILY SUPPORT GROUPS & RESOURCES THROUGHOUT NEBRASKA

**Denotes organization which can be found on Facebook by the same name. Note: most are closed groups and require permission to be a member. Simply send a request to acquire access.*

Down Syndrome Advocates in Action Nebraska*

A non-profit created to help individuals with Down syndrome and those around them become confident advocates. Offering help with: peer presentations, app/technology ideas, IEP support, and more.

402.413.0199
dsaaofne@gmail.com
www.dsaane.org

Down Syndrome Alliance of the Midlands*

A non-profit located in Omaha committed to connecting those touched by Down syndrome through education, advocacy and support whose efforts include: Parent Outreach, Education Advocacy and Medical Outreach. Search @ omahadownsyndrome on Facebook.

402.554.6095
www.dsamidlands.org

Kearney Area Down Syndrome Support Group*

A local support group based in Kearney.

www.kearneydownsyndrome.org

Nebraska Department of Health and Human Services

www.DHHS.ne.gov/Down_syndrome

Norfolk Area Down Syndrome Support Group*

A small group of families with children who have Down Syndrome.

402.360.1150

Northeast Nebraska Down Syndrome Association*

Dedicated to raising the awareness of Down Syndrome to people and communities in northeast Nebraska.*

402.841.9376
www.nendsa.org

O.N.E. Coalition

Organizations Networking for Everyone with Special Needs - DSAF is proud to contribute to and collaborate with this coalition to sponsor events for children with Down syndrome, autism, cerebral palsy, and other developmental or intellectual disabilities.

onecoalition@gmail.com
www.onecoalition.weebly.com

PTI Nebraska - Early Childhood *(students ages 0-5)*

Informed Parents = Improved outcomes for Families. A statewide resource for families of children with disabilities and special health care needs.

(PTI Nebraska - Early Childhood, continued)

Contact: Connie Shockley, Parent Support Coordinator

402.403.3911

866.991.6713

402.346.0525

cshockley@pti-nebraska.org

www.pti-nebraska.org

PTI Nebraska

PTI Nebraska provides training, information and support to Nebraska parents and others who have an interest in children from birth through twenty-six and who receive or who might need special education or related services. They enable parents to have the capacity to improve educational outcomes for all children.

402.346.0525

800.284.8520

www.pti-nebraska.org

Region V

The primary purpose of Region V Services is to help individuals with developmental disabilities achieve their life goals.

402.471.6400

www.region5services.com

The Arc

The mission of the Arc of Lincoln is to empower people with developmental disabilities and their families to promote and protect their rights and interests, while enriching the quality of their lives.

The Arc of Lincoln

402.421.8866

director@arclincoln.org

www.arclincoln.org

The Arc of Nebraska

402.475.4407

info@arc-nebraska.org

www.arc-nebraska.org



LINCOLN/OMAHA AREA PEDIATRIC THERAPY SERVICE PROVIDERS

This list contains a few of the Lincoln area service providers that provide therapeutic services typically needed for children with Down syndrome. It is not an all-inclusive list.

Barkley Speech-Language and Hearing Clinic

The UNL Barkley Speech-Language and Hearing Clinic is located in the Barkley Memorial Center on the University of Nebraska-Lincoln's East Campus at 42nd and Holdrege Streets. Services for individuals with speech, language, hearing and other disabilities are available as a part of academic programs in Speech-Language Pathology and Audiology.

University of Nebraska
253 Barkley Memorial Center
Lincoln, NE 68583-0731
402.472.2071

<http://cehs.unl.edu/secd/barkley-speech-language-hearing-clinic/>

Boys Town National Research Hospital

The Boys Town National Research Hospital is located in Omaha, Nebraska and is a leader in clinical and research programs focusing on childhood deafness, visual impairment and related communication disorders.

555 North 30th Street
Omaha, NE 68131
402.498.6540

www.boystownhospital.org

Bryan Medical Center Pediatric Therapy

Speech, Occupational Therapy, Physical Therapy, Feeding Therapy.

1500 S. 48th St, Edwards Tower, Suite 709
Lincoln, NE
402.481.3316

www.bryanhealth.org/pediatric-therapy

Early Development Network

Early intervention services are offered to your child FREE OF CHARGE based on the diagnosis of Down syndrome. To enroll, call the number below. Types of services provided are: Physical, Occupational, and Speech Therapy. Local school district provided home-based therapy services.

402.471.2447
888.806.6287

<http://edn.ne.gov/cms/>

Handprints and Footsteps

Provides therapy services for children with a wide variety of conditions. Services include physical therapy, occupational therapy, speech therapy, water therapy, and assessments for orthotics.

(Handprints and Footsteps, continued)

5930 VanDervoort Dr Suite A
Lincoln, NE 68516
402.420.2099

www.handprintsandfootsteps.com

Madonna Rehabilitation Hospital

One of the nation's foremost providers for medical and physical rehabilitation for adults and children. Specializing in pediatric rehabilitation, Madonna offers hope and healing to thousands of patients from throughout the country each year.

Lincoln Campus

5401 South St.
Lincoln, NE 68506
800.676.5448
402.413.3900
info@madonna.org
www.madonna.org



Omaha Campus

17500 Burke St.
Omaha, NE 68118

402.401.3100
info@madonna.org
www.madonna.org

Monroe-Meyer Institute

The Institute offers genetics clinics in Omaha, and in Kearney, North Platte and Scottsbluff on a quarterly basis. Provides interdisciplinary family-centered services and supports for consumers and all individuals with disabilities.

University of Nebraska Medical Center

42nd and Emile
Omaha, NE 68198
402.559.6418

800.559.3937, ext 96418
www.unmc.edu/mmi



Scottish Rite Masons Clinic for Children with Language Disorders

Free speech/language clinics providing services to children. In Nebraska, the clinics are located in Lincoln, Omaha, and Hastings. The services are provided at no cost to families.

University of Nebraska
253 Barkley Memorial Center (East Campus)
Lincoln, NE 68583-0731
Contact Carrie Kenny: 402.472.0642

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 Adoption Network

Provides a registry of over 200 families interested in adopting infants with Down syndrome. Adoptive families are located all across the United States and Canada and must be approved for adoption by a licensed agency in their state of residence.

Contact: Robin Steele, coordinator at 513.213.9615

rsteele@zoomtown.com

www.ndsan.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

Down Syndrome Guild of Greater Kansas City

Provide support and resources, encourage active participation in the community, foster positive attitudes, and help individuals with Down syndrome reach their full potential. They are a nice additional resource to families and have a website that is easy to navigate.

913.384.4848

fax: 913.384.4949

24-hour information line: 913.384.9898

info@kcdsg.org

www.kcdsg.org





BREASTFEEDING

Canadian National Down Syndrome Society

ndscenter.org/wp-content/uploads/CDSS_breastfeeding_brochure.pdf

Julia's Way

A 501c3 non-profit organization dedicated to inspiring parents, medical professionals, and the general public to reimagine what's possible for those living with Down syndrome through education, advocacy, and awareness.

The organization's current project focuses on inspiring and encouraging mothers of children with Down syndrome to breastfeed their babies as well as educating medical professionals on how to support mothers to help their babies breastfeed successfully.

love@juliasway.org

<https://juliasway.org/breastfeedingresources>

www.juliasway.org

La Leche League

www.lalecheleague.org/faq/down.html

MilkWorks Lincoln | Omaha

A comprehensive breastfeeding support center, offering breastfeeding consultations, breast pumps, breastfeeding supplies, and a wide variety of education and support services.

MilkWorks O*

Rockbrook Village

Omaha

402.502.0617

omaha@milkworks.org

www.milkworks.org

MilkWorks Lincoln*

5930 South 58th Street, Suite W

Lincoln

402-423-6402

information@milkworks.org

www.milkworks.org



www.dsafnebraska.org

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