Resource Booklet for Children With Metabolic Disorders

NORTH DAKOTA
DEPARTMENT *of* HEALTH
Children's Special Health Services

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Disclaimer
The content within this booklet is for informational purposes only. It is not intended to be a substitute for professional medical advice. Families are encouraged to discuss the information in this booklet with their child's doctor or other health-care providers.

Specialty Health Services

For many children with metabolic disorders, evaluation by an experienced team of professionals is necessary for optimal treatment. Families are an essential partner to the team as they are the principle caregiver and the center of strength and support for the child. The links below provide access to information on many metabolic disorders and their diagnosis, management or treatment:
http://ghr.nlm.nih.gov/conditionCategory/food-nutrition-and-metabolism
www.ndhealth.gov/newbornscreening/factsheets.htm

Clinics and Programs

Children's Special Health Services (CSHS) funds a metabolic disorders clinic for children with Phenylketonuria (PKU), Maple Syrup Urine Disease (MSUD), MCAD and other metabolic disorders in Fargo, N.D. This CSHS supported clinic provides multidisciplinary team evaluations where families have an opportunity to see many different providers in one place at one time. Reports generated from the clinic visit include recommendations to help direct care for the coming year. All children who might benefit are eligible to attend with no direct cost to the family. For more information, review the following link: www.ndhealth.gov/cshs/docs/clinic-schedule.pdf.

Clinics make a positive difference in children's overall care. Families report that clinics provide:

- Information, education and reassurance.
- Diagnostic evaluation and treatment.
- Coordinated/comprehensive care.
- Follow-up and monitoring.
- Access to specialty medical care.

Metabolic Disorders Clinic

Services: Coordinated, multidisciplinary clinics are held quarterly. Support for family travel and lodging expenses may be available.

Sanford Broadway Building
737 N. Broadway
Fargo, ND 58122
701.234.6600
Toll free: 800.828.2901, #2 Option

Metabolic Food Program

The metabolic food program provides medical food and low-protein modified food products to individuals with PKU and MSUD. For more information contact CSHS at:
701.328.2436
Toll free: 800.755.2714

Other Low-Protein Food and Formula Assistance

Formula and low-protein food companies may offer varying degrees of assistance. The following is a list of examples, but not representative of all companies.

- Cambrooke Foods offers assistance with low-protein food products through their Green Light program. An application is available at: www.cambrookefoods.com/included/docs/GL_Application.pdf.
- Mead Johnson offers the Helping Hands formula assistance program to infants younger than 1. To learn more go to: www.patientassistance.com/profile/meadjohnsonnutritionals-177/.
- Abbott-Ross may offer assistance to individuals that are not covered by a public or private entity. They do have financial criteria, but do not limit according to age. To learn more go to www.abbottpatientassistancefoundation.org or call toll-free at 800.222.6885.

Phenylalanine (Phe) Testing

Newborns born in North Dakota are tested for the following metabolic diseases: phenylketonuria, hypothyroidism, galactosemia, congenital adrenal hyperplasia, biotinidase deficiency, sickle cell disease, other hemoglobinopathies, and any other disease that can be identified through tandem mass spectrometry that is designated on the North Dakota Department of Health's test schedule. Ongoing PKU testing is available for individuals in order to monitor Phe levels. For testing supplies, contact the North Dakota Department of Health at 800.472.2286.

Insurance

Insurance Coverage for Metabolic Food and Formula: The cost of special metabolic formulas and special low-protein foods may be reimbursed by insurance companies. State law mandates insurance policies cover medical food and low-protein modified food products that have been determined medically necessary by a physician for the treatment of inherited metabolic disease.

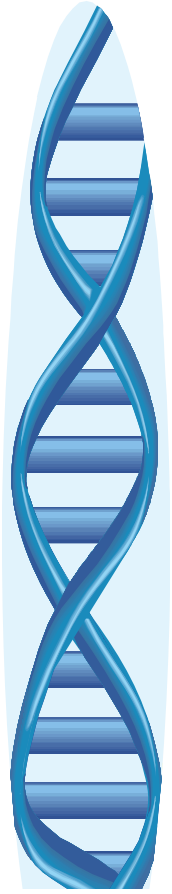
For more information, a "Helpful Hints about Insurance Reimbursement" fact sheet is available on the Children's Special Health Services (CSHS) website.
www.ndhealth.gov/cshs/links.htm

Assistance

CSHS can pay for special formula when children birth to age 21 are medically and financially eligible for the Treatment Program. For more information, call 800.755.2714.

Genetic Services

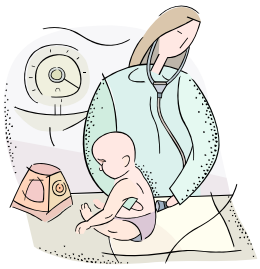
Genetic/birth defects evaluation and counseling services are available throughout the state. For more information, call CSHS toll-free at 800.755.2714 or contact the following:



Division of Medical Genetics
Department of Pediatrics
School of Medicine and Health Sciences Room 5910
501 Columbia Road North STOP 9037
Grand Forks, ND 58201
Telephone: 701.777.4277 or 701.772.5301
www.med.und.nodak.edu/pediatrics/genetics

Sanford Health Medical Genetics
737 Broadway North
Fargo, ND 58102
Telephone: 701.234.2362
www.north.sanfordhealth.org/

Informed Medical Decisions (telehealth genetic counseling services)
North Dakota Contact - Marie Schuetzle, MS, CGC
Senior Genetic Counselor
Telephone: 760.230.4251
Fax: 760.203.1194
www.informedDNA.com



Health-Care Providers

Metabolic disorders can often best be managed by a metabolic clinic team. In North Dakota care providers may include:

- Child Psychologist
- Education Specialist
- Nurse Clinic Coordinator
- Pediatric Endrocrinologist
- Prenatal/Pediatric Nutrition Specialist
- Social Worker

For a list of CSHS participating specialists, contact CSHS at 800.755.2714.
www.ndhealth.gov/cshs/provider.htm

Family Support Services

Anne Carlsen Center (ACC) offers a rich tradition of empowering individuals with disabilities and their families. Their experienced staff provides compassion, training, services and supports in homes and communities across North Dakota. On the Jamestown campus, they meet the educational, residential and therapeutic needs of children and young adults with autism, behavior disorders, medical fragility and other developmental disabilities. They also provide services in the home through customized supports for individuals from birth to age 21.
www.annecenter.org

701 3rd Street NW — 701.252.3850
Jamestown, ND 58401 — Toll-free: 800.568.5175

Care Coordination for Children with Special Health-Care Needs is a program intended to assist families who have children with complex needs. The Care Coordination Program through Children's Special Health Services (CSHS) helps eligible families access services and resources in their community, and when needed, across multiple service delivery settings. For more information, refer to the following websites:

- Medical Home –
  www.medicalhomeinfo.org
- Grand Forks Public Health –
  http://grandforksgov.com/gfgov/Health.nsf/Pages/Care+Coordination
- County Social Services –
  www.nd.gov/dhs/locations/countysocialserv/index.html
- North Dakota Integrated Services –
  www.ndcpd.org/ndis

Child Care Assistance Program

Services: Provides financial assistance to low-income families for child care costs.
North Dakota Department of Human Services
600 East Boulevard, Dept 325, Bismarck, ND 58505
701.328.2332 Public Assistance Toll Free Number: 800.755.2716
www.nd.gov/dhs/services/financialhelp/childcare.html

Child Care Resource and Referral

Services: Assistance locating child care and other related services.
Bismarck – 701.223.1510 or 888.223.1510 — Grand Forks – 701.772.3435 or 888.778.3435
Minot – 701.838.7800 or 800.450.7801 — Fargo – 218.299.7026 or 800.941.7003
Jamestown – 701.252.0350 or 888.767.0350
http://www.ndchildcare.org

Disability Services Division provides services to North Dakota citizens of all ages with developmental disabilities. Call your regional Human Service Center or the Disability Services Division at 800.755.8529.
www.nd.gov/dhs/services/disabilities

- Family Care Option provides respite care to families through short-term foster home placement.
- Family Subsidy Program provides financial help needed by the family to care for the child at home.
- Infant Development Program provides intervention services in the home or other natural settings by trained professionals to promote optimum development of children from birth through age 2.
- Respite Care Program provides services of a specially trained caregiver to provide the family with occasional relief from the stress of providing care.
- Right Track provides child development consultations for children from birth to age 3. For more information, call 800.755.8529.
- Supportive Home Care assists with and teaches parents about the special care the child needs.
- Experienced Parent Program provides support services to parents with children enrolled in early intervention.

Family Voices of ND is a health information and education center, which includes the Parent to Parent Project, a program that offers emotional support to families.
701.493.2634 or 888.522.9654
www.fvnd.org

FamNet supports collaboration between family support organizations to improve health outcomes for families of children, youth and adults with special health-care needs and/or disabilities. Partner agencies have come together to develop a portal to help guide others to agencies that will best help meet family needs.
www.ndcpd.org/ndfamnet

Federation of Families provides support and advocacy for children's mental health.
701.250.1795 or 800.492.4951
www.fcsn.org

Legal Services of North Dakota
P.O. Box 1893
Bismarck, ND 58502-1893
701.222.2110 or 800.634.5263

National Alliance on Mental Illness North Dakota
P.O. Box 3215
Minot, ND 58702-3215
701.857.3345

National Dissemination Center for Children with Disabilities (NICHCY) is an information clearinghouse that provides free information about disabilities and disability-related issues. For more information, call 800.695.0285.
www.nichcy.org

Pathfinder Services of North Dakota, Inc.
Family Training and Information Center
1600 2nd Avenue SW, Ste. 19
Minot, ND 58701
701.837.7500 or 800.245.5840
TDD: 701.837.7501 Fax: 701.837.7548
www.pathfinder-nd.org

Protection and Advocacy Project
400 E. Broadway, Ste. 409
Bismarck, ND 58501
701.328.2950 or 800.472.2670
Fax: 701.328.3934
TTY: 800.366.6888
www.ndpanda.org

Regional Resource Centers for Independent Living provides services that help young people with disabilities with transition from home and school to the work place and independent living.
www.freedomrc.org/links.html

Dakota Center for Independent Living
311 East Broadway
Bismarck, ND 58501
701.222.3636 or 800.489.5013

Options Interstate Resource Center
318 3rd St NW
East Grand Forks, MN 56721
218.773.6100 or 800.726.3692

Freedom Resource Center
2701 9th Avenue S, Ste. H
Fargo, ND 58103
701.478.0459 or 800.450.0459

Independence, Inc.
300 3rd Avenue SW, Ste F
Minot, ND 58701
701.839.4724 or 800.377.5114

Ronald McDonald House Charities provides a temporary residence near the medical facility where family members can sleep, eat, relax and find support from other families in similar situations. In return, families are asked to make a donation, but if that isn't possible, the stay is free.

Bismarck: 609 N. 7th Street, Bismarck, ND 58501 701.258.5076 www.rmhcbismarck.com
Fargo: 1330 18th Ave South, Fargo, ND 58103 701.232.3980 www.rmhcfargo.org

Information and Referral Services

Children's Special Health Services (CSHS)

North Dakota Department of Health
State Capitol – Judicial Wing
600 East Boulevard Avenue, Dept 301
Bismarck, ND 58505-0200
701.328.2436
Toll-free: 800.755.2714
Relay TDD: 701.328.3975
E-mail: dohcshsadm@nd.gov

Children's Special Health Services is a program that helps children with special health-care needs and their families. Individuals are encouraged to call CSHS for free health-care information. CSHS can also help with referrals to health-care providers and special programs for children with chronic health conditions.

www.ndhealth.gov/cshs

County Social Services

Administers economic assistance and social service programs. To inquire about assistance, please check your local phone book under county government.

www.nd.gov/dhs/locations/countysocialserv

Pediatricians and Family Doctors

Lists of primary care doctors who practice in North Dakota are available upon request. All children benefit from a medical home. A medical home is not a building, but rather an *approach* to providing comprehensive medical care. In a medical home, a physician or other medical provider works in partnership with the family/patient to assure that the medical and non-medical needs of the child/youth are met. Through this partnership, the medical provider can help the family/patient access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

Public Health

Local public health units provide a variety of services such as immunizations, home visits, high-risk infant follow-up, general child health services, community wellness programs, and school health screenings.

www.ndhealth.gov

Organizations

National Newborn Screening & Genetics Resource Center (NNSGRC)

The National Newborn Screening and Genetics Resource Center is a cooperative agreement between the Maternal and Child Health Bureau, Genetic Services Branch and the University of Texas Health Science Center at San Antonio, Department of Pediatrics. Information and resources are provided in the area of newborn screening and genetics to benefit health professionals, the public health community, consumers and government officials.
http://genes-r-us.uthscsa.edu/

If you would like to join the NNSGRC discussion listserv on newborn screening, send a request to Brad Therrell Ph.D. at www.therrell@uthscsa.edu.

PKU News

National PKU News is a non-profit organization located in Seattle, Washington. It is dedicated to providing up-to-date, accurate news and information to families and professionals dealing with phenylketonuria.
www.pkunews.org/index.htm

Interagency Project for Assistive Technology (IPAT)

Services: Information and referral, training, technical assistance to systems and individuals, equipment loan library, outreach activities, a link between state and private entities, resource development, alternative loan program, and dissemination of assistive technology materials based on consumer input.

P.O. Box 743	3509 Interstate Boulevard	400 East Broadway
Cavalier, ND 58220	Fargo, ND 58103	Bismarck, ND 58501
701.265.4807 or	701.365.4728 or	701.355.4615 or
800.265.4728	800.895.4728	888.540.4728

www.ndipat.org

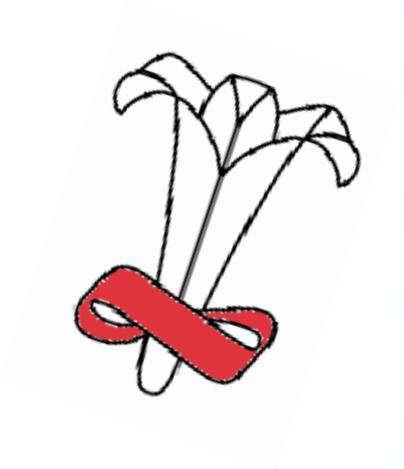
North Dakota Center for Persons with Disabilities

Minot State University
500 University Avenue West
Minot, ND 58707
701.858.3000 or 800.777.0750
www.ndcpd.org/

Easter Seals Goodwill ND, Inc.

Services include, but are not limited to: Respite or relief care, personal care services and domestic homemaker services, equipment loan, advocacy for individuals with disabilities, and information and referral.

Dickinson:	2125 Sims Street PO Box 361 Dickinson, ND 58602-0361 866.895.1587
Fargo:	15 South 21st, Suite 105 Fargo, ND 58103-1435 866.895.1588
Grand Forks:	3651 South Washington Street Grand Forks, ND 58201-7201 866.876.1015
Jamestown:	203 Business Loop West PO Box 756 Jamestown, ND 58402-0756 866.897.6004
Mandan:	211 Collins Avenue PO Box 1206 Mandan, ND 58554-1206 701.663.6828 Toll-free: 800.247.0698 www.esgwnd.net
Minot:	800 12th Avenue South West Minot, ND 58701-9114 866.895.1589



North Dakota Chapter of the March of Dimes Birth Defects Foundation

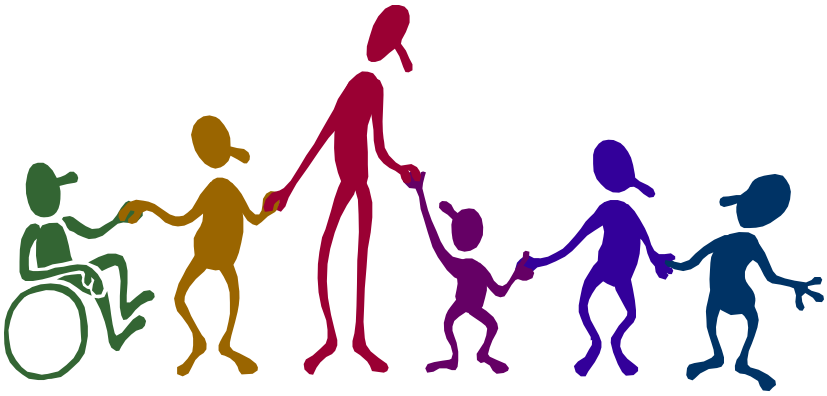
1330 Page Drive, Ste. 102
Fargo, ND 58103
701.235.5530
www.marchofdimes.com/northdakota/northdakota.asp

Project HERO

Services: HERO provides unused medical supplies and donated durable medical equipment to those in need. HERO works with several agency and health-care partners to redistribute viable medical products to the medically fragile and financially challenged.
5012 53rd Street S, Suite C
Fargo, ND 58104
218.284.6111
www.fmhero.org

Shriners Hospitals for Children-Twin Cities

Services: Provides care for children (17 and younger) with orthopedic problems and burns. Some of the common orthopedic problems treated at Shriners include scoliosis, osteogenesis imperfecta, orthopedic problems of cerebral palsy, hand problems, back problems, limb deficiencies and growth problems, orthopedic problems of spina bifida with myelodysplasia, club foot and dislocated hip, leg-length discrepancies, orthopedic problems resulting from neuromuscular disorders, legg-perthes disease, rickets, and juvenile rheumatoid arthritis. Evaluation clinics are offered throughout North Dakota. For more information, call Shriners Hospital for Children –Twin Cities at 888.293.2832 or the patient referral line at 800.237.5055.
www.shrinershq.org



The Arc of North Dakota

Services: The Arc is a member and volunteer-driven nonprofit organization that offers advocacy, education and family support to children and adults with intellectual disabilities and related developmental disabilities and their families.

Bismarck:	The Arc of Bismarck 1211 Park Avenue Bismarck, ND 58504 701.222.1854 www.thearcofbismarck.org/
Dickinson:	The Arc of Dickinson PO Box 1421 Dickinson, ND 58601 701.483.4272
Fargo:	The Arc of Cass County 255 North University Drive Fargo, ND 58102 701.293.8191 www.arccassnd.com
Grand Forks:	Arc, Upper Valley, Inc. 2500 Demers Ave P.O. Box 12420 Grand Forks, ND 58208-2420 701.772.6191 www thearcuppervalley.com
Valley City:	The Arc of Barnes County 700 11th Street NW #135 Valley City, ND 58072 701.845.5845

Libraries

North Dakota State Library – 701.328.4622 or toll-free at 800.472.2104
www.library.nd.gov
Children's Special Health Services Library – toll-free at 800.755.2714
www.ndhealth.gov/cshs/docs/cshs-resource-catalog.pdf
Pathfinder Services of North Dakota Library – toll-free at 800.245.5840
www.pathfinder-nd.org/lib.html
Prevention Resource Center – toll-free at 800.642.6744
(topics in mental health, substance abuse, aging and disabilities)
http://odinlibrary.org/ndspr.html

Education

Head Start
Head Start and Early Head Start are comprehensive child development programs. Regular Head Start programs are for children ages 3 and 4. Some communities offer a program specifically for families with children younger than 3 and pregnant women. A variety of services are provided through Head Start programs, including health, education, parent involvement, family literacy, social services and services for children with disabilities. Call the Head Start State Collaboration office at 800.245.3736 or your local Head Start program.
www.nd.gov/dhs/services/childfamily/headstart

School Nursing
The purpose of school nursing is to support the educational process by contributing positively and significantly to the health, health attitudes and health behaviors of today's children, and consequently, tomorrow's adults. Contact the Department of Health at 701.328.2493 or your local school nurse.
www.ndhealth.gov/school-nursing

Special Education
It is important to locate and identify children who are in need of special services as early as possible. Screening and assessment opportunities offered at school help identify possible areas of difficulty that could interfere with a child's learning or academic performance. Some children with disabilities may require special education services to address their unique educational needs. Contact the Department of Public Instruction at 701.328.2260 or your local special education unit.
www.dpi.state.nd.us

Financial Help

Bridge to Benefits is a multi-state project sponsored by the Children's Defense Fund – Midwest Region focused on improving the well-being of families and individuals by linking them to public work support programs and tax credits.
nd.bridgetobenefits.org

Caring for Children provides free health and dental coverage to children of low-income working parents. Children are eligible if they are North Dakota residents, birth through age 18, and are not covered by other health insurance or not eligible for Medicaid or Healthy Steps. Parents must meet income requirements. For more information or to apply, call 701.277.2227 or toll-free at 800.342.4718.
www.ndcaring.org

Children's Special Health Services (CSHS)
Diagnostic Services – CSHS pays for health-care visits and tests needed to diagnose many chronic health conditions seen in children. To qualify, children must be suspected of having a CSHS-eligible condition. There is no financial eligibility requirement for diagnostic services; however, insurance or other sources of health-care coverage are used when available. Health-care visits must be made with a specialist who is approved to provide services through CSHS.

Treatment Services – In North Dakota, several programs are available that provide health care coverage for children. CSHS is a program specifically for children with special health-care needs. CSHS pays for specialty care that is needed to treat a CSHS-eligible condition. To qualify, families must meet income eligibility guidelines currently set at 185 percent of the federal poverty level. Families with incomes higher than 185 percent still may be eligible with a cost share. Insurance or other sources of health-care coverage are used when available. Health-care visits must be made with a specialist who is approved to provide services through CSHS.

Families apply for CSHS diagnostic and treatment services at their local county social service office. In order to ensure coverage, contact CSHS toll free at 800.755.2714, as provider restrictions and time limits may affect the eligibility start date.
www.ndhealth.gov/cshs/docs/cshs-diagnostic-and-treatment-services-fact-sheet.pdf

Comprehensive Health Association of North Dakota (CHAND) provides comprehensive health insurance to residents of the state who are denied health insurance or are considered high risk. Individuals must be a resident of North Dakota continuously for at least six months and have written evidence from at least one insurance carrier that within the last six months they have been denied health-care coverage or offered coverage which substantially restricts benefits for specific conditions. For more information, call 800.737.0016.
www.chand.org

Vision Coverage

Vision USA provides basic eye health and vision care services free of charge to uninsured, low-income people and their families.
701.258.6766
www.aoa.org/visionusa.xml

VSP Sight for Students is a charity that provides free vision exams and glasses to low-income, uninsured children.
888.290.4964
www.sightforstudents.org

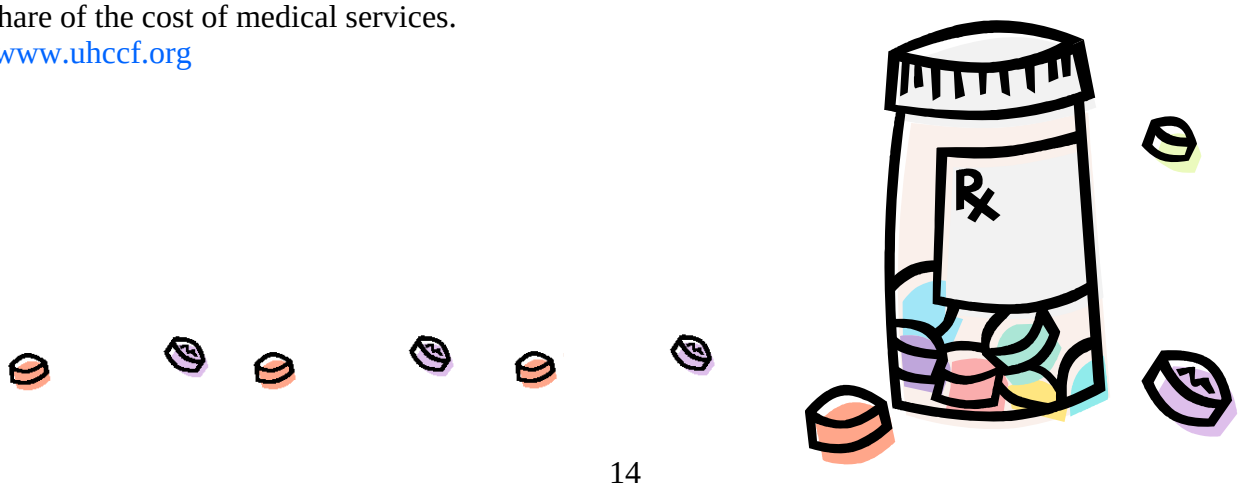
Prescription Coverage

ND Prescription Drug Repository Program collects and distributes donated medications from hospitals, hospices and other facilities so that pharmacies and physicians can dispense them to those who struggle paying for prescriptions regardless of insurance coverage. The medications and supplies are unopened and secure but cannot be resold to patients.
www.nodakpharmacy.com

Prescription Connection for North Dakota is a program of the North Dakota Insurance Department that connects kids and families with free and discounted prescription drugs direct from the pharmaceutical manufacturer.
888.575.6611
www.rxconnectnd.org

Health-Care Program

United Health Care Children's Foundation embraces and supports the concept of facilitating access to health-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child and that are not fully covered by the available commercial health benefit plan. The Foundation provides financial assistance toward the family's share of the cost of medical services.
www.uhccf.org



Dental Coverage

Safety Net Dental Clinics are programs that usually see patients who do not have other access to dental care. The patients typically are covered by Medicaid or the clinic offers sliding fee schedules or reduced fees.

- Bridging the Dental Gap is a nonprofit community dental clinic serving low-income and uninsured individuals in the Bismarck-Mandan area.
  701.221.0158
- Family Healthcare Center Dental Clinic is a federally qualified community health center serving low-income and uninsured individuals within the Fargo Red River Valley Region.
  701.271.3332
- Red River Valley Dental Access Project serves low-income, uninsured and Medicaid-eligible individuals who have urgent dental pain and do not have access to a dentist in Fargo-Moorhead.
  701.364.5364
- Valley Community Health Center Dental Clinic is a federally qualified health center serving low-income, uninsured and insured individuals of all ages in the Northern Red River Valley.
  701.757.2100

North Dakota Donated Dental Services is a network of volunteer dentists who provide dental care to the state's most vulnerable people: disabled, elderly or medically compromised individuals who cannot afford necessary treatment nor get public aid.
866.572.9390
www.ndhealth.gov/oralhealth/Publications/Fact_Sheet_Dental%20Access.pdf

Jerene's Wish is a program that provides orthodontic treatment at a minimal cost to eligible children. For more information contact Warford Orthodontics.
701.255.1311
info@warfordorthodontics.com

Medicaid pays for health services for qualifying families with children and people who are pregnant, elderly or disabled. Screening, diagnosis and treatment for children younger than 21 is provided through the Health Tracks Program. For more information or to apply, contact your county social service office.
www.nd.gov/dhs/services/medicalserv/medicaid

ND Healthy Steps is for children age 18 or younger who do not have health insurance, do not qualify for North Dakota Medicaid and live in families with qualifying income. Call 877.543.7669 for an application.
www.nd.gov/dhs/services/medicalserv/chip

North Dakota Association for the Disabled, Inc. (NDAD) may provide some financial assistance for individuals with disabilities. For more information, call the office nearest you:

- Grand Forks 2660 South Columbia Road, Grand Forks, ND 58201
  701.775.5577or 800.532.6323
- Minot 1808 20th Avenue SE, Minot, ND 58701
  701.838.8414 or 888.999.6323
- Williston 309 Washington Avenue, Williston, ND 58801
  701.774.0741or 877.777.6323
- Bismarck 400 E Broadway Avenue, Ste. 306, Bismarck, ND 58501
  701.355.4615 or 888.540.4728
- Fargo 3509 Interstate Boulevard, Fargo, ND 58103
  701.281.8215 or 888.363.6323

Services: Information and referral, advocacy, equipment donations and financial assistance.
www.ndad.org

Supplemental Security Income (SSI) provides monthly payments for children who meet disability and financial eligibility requirements. For more information, contact the Social Security Administration.
North Dakota toll-free: 877.319.6044 or National toll-free: 800.772.1213
www.ssa.gov

Women, Infants and Children (WIC) provides nutritious foods, offers information about how to feed your family, and helps you participate in other important health programs. Pregnant women, breastfeeding women and children up to age 5 who meet WIC's liberal income guidelines are eligible to participate. For more information, contact 800.472.2286 or your county WIC office as listed in the phone book.
www.ndhealth.gov/wic

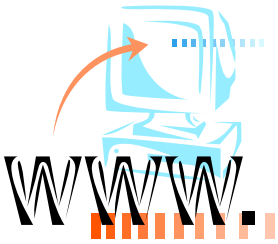
Websites

Condition-Specific Websites:

Abbott Ross: www.abbottpatientassistancefoundation.org
Baby's First Test: www.nbsclearinghouse.org/
Cambrooke Foods: www.cambrookefoods.com
Centers for Disease Control and Prevention: www.cdc.gov/ncbddd/pediatricgenetics/newborn_screening.html
Genetic Alliance: www.geneticalliance.org/nbs
Mayo Clinic: www.mayoclinic.org/metabolic-disorders/
Mead Johnson: www.enfamil.com/app/iwp/enf10/content.do?dm=enf&id=/Consumer_Home3/FeedingSolutions/Metabolics&iwpst=B2C&ls=0&csred=1&r=3490029312
National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives: www.nccrcg.org/AM/Template.cfm?Section=Home5&Template=/Templates/TemplateHomepage/NCCRCG_1502_20070809T145305_LayoutHomePage.cfm
National Information Centre for Metabolic Diseases: www.climb.gov.uk
National Newborn Screening & Genetics Resource Center: http://genes-r-us.uthscsa.edu/
Needy Meds: www.needymeds.org
Save Babies Through Screening Foundation: www.savebabies.org

Additional Websites for Families of Children With Special Health-Care Needs:

Bright Futures: www.brightfutures.org
CDC Parent Portal: www.cdc.gov/parents
Dr. Greene's House Calls: www.drgreene.com
Early Intervention: www.nd.gov/dhs/services/disabilities/earlyintervention
Family Village: www.familyvillage.wise.edu
Gillette Children's Specialty Healthcare: www.gillettechildrens.org
Healthy Children: www.HealthyChildren.org
Healthy & Ready To Work (HRTW): www.hrtw.org
Institute for Child Health Policy (ICHP): www.ichip.edu
Kids As Self Advocates (KASA): www.fvkasa.org
Mayo Health Clinic: www.mayoclinic.com
Medical Home National Center: www.medicalhomeinfo.org
Medical Home Portal: www.medicalhomeportal.org
MUMS (parent support): www.netnet.net/mums
National Organization for Rare Disorders (NORD): www.rarediseases.org
Need to Know: www.ndcpd.org/n2k
ParentsPlace: http://parenting.ivillage.com
Social Security Administration: www.ssa.gov
Starlight/Starbright Children's Foundation: www.starlight.org
University of Minnesota Children's Center: www.uofmchildernshospital.org



Statewide Tribal Programs

Fort Berthold Indian Reservation

www.mhanation.com/main/main.html

Three Affiliated Tribes

• MinneTohe Health Center		701.627.4701
• Community Health Representative	New Town	701.627.3653
	Mandaree	701.759.3441
	Parshall	701.862.3872
	Twin Buttes	701.938.4574
	White Shield	701.743.4178

Standing Rock Indian Reservation

www.standingrock.org

• Public Health Service Hospital		701.854.3831
• IHS Clinics – Cannonball, ND		701.854.3453
• Community Health Representative	Fort Yates	701.854.3856
	Cannonball	701.854.9926
• Tribal Health		701.854.7206

Fort Totten Indian Reservation

www.spiritlakenation.com

Spirit Lake Nation

• Indian Health Service Clinic	701.766.1600
• Maternal Child Health	701.766.1251
• Tribal Health	701.766.4236
• Community Health Representative	701.766.4238
• Early Childhood Tracking	701.766.1232

Trenton Indian Service Area

www.ndhealth.gov/localhd/TISA

• Trenton Community Clinic	701.774.0461
• Community Health Representative Coordinator	701.774.0303
• Tribal Health	701.774.0461

Turtle Mountain Indian Reservation

www.tmbci.net

• Quentin Burdick Health Facility	701.477.6111
• Community Health Representative	701.477.5696
• Tribal Health	701.477.8469

Notes:

NORTH DAKOTA
DEPARTMENT *of* HEALTH
Children's Special Health Services

600 East Boulevard Avenue, Dept. 301
Bismarck, N.D. 58505-0200
701.328.2436 or 800.755.2714
Fax: 701.328.1645
E-mail: dohcshsadm@ndgov
www.ndhealth.gov/cshs/

Revised 12-01-11