



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

600 East Boulevard Avenue, Dept. 301

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701.328.2436 or 800.755.2714

Fax: 701.328.1645

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[www.ndhealth.gov/cshs/](http://www.ndhealth.gov/cshs/)

Revised 12-01-11

# Resource Booklet for Children With Metabolic Disorders



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



# Notes:

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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](http://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](http://www.ndhealth.gov/cshs/docs/clinic-schedule.pdf).

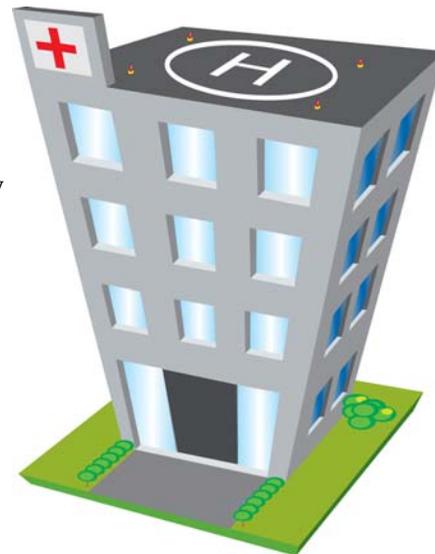
Clinics make a positive difference in children's overall care. Families report that clinics provide:

- 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



## Statewide Tribal Programs

### Fort Berthold Indian Reservation

[www.mhanation.com/main/main.html](http://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](http://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](http://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](http://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](http://www.tmbci.net)

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



## Websites

### Condition-Specific Websites:

**Abbott Ross:** [www.abbottpatientassistancefoundation.org](http://www.abbottpatientassistancefoundation.org)

**Baby's First Test:** [www.nbsclearinghouse.org/](http://www.nbsclearinghouse.org/)

**Cambrooke Foods:** [www.cambrookefoods.com](http://www.cambrookefoods.com)

**Centers for Disease Control and Prevention:** [www.cdc.gov/ncbddd/pediatricgenetics/newborn\\_screening.html](http://www.cdc.gov/ncbddd/pediatricgenetics/newborn_screening.html)

**Genetic Alliance:** [www.geneticalliance.org/nbs](http://www.geneticalliance.org/nbs)

**Mayo Clinic:** [www.mayoclinic.org/metabolic-disorders/](http://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](http://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](http://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](http://www.climb.gov.uk)

**National Newborn Screening & Genetics Resource Center:** <http://genes-r-us.uthscsa.edu/>

**Needy Meds:** [www.needymeds.org](http://www.needymeds.org)

**Save Babies Through Screening Foundation:** [www.savebabies.org](http://www.savebabies.org)

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

**Bright Futures:** [www.brightfutures.org](http://www.brightfutures.org)

**CDC Parent Portal:** [www.cdc.gov/parents](http://www.cdc.gov/parents)

**Dr. Greene's House Calls:** [www.drgreene.com](http://www.drgreene.com)

**Early Intervention:** [www.nd.gov/dhs/services/disabilities/earlyintervention](http://www.nd.gov/dhs/services/disabilities/earlyintervention)

**Family Village:** [www.familyvillage.wise.edu](http://www.familyvillage.wise.edu)

**Gillette Children's Specialty Healthcare:** [www.gillettechildrens.org](http://www.gillettechildrens.org)

**Healthy Children:** [www.HealthyChildren.org](http://www.HealthyChildren.org)

**Healthy & Ready To Work (HRTW):** [www.hrtw.org](http://www.hrtw.org)

**Institute for Child Health Policy (ICHIP):** [www.ichip.edu](http://www.ichip.edu)

**Kids As Self Advocates (KASA):** [www.fvkasa.org](http://www.fvkasa.org)

**Mayo Health Clinic:** [www.mayoclinic.com](http://www.mayoclinic.com)

**Medical Home National Center:** [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)

**Medical Home Portal:** [www.medicalhomeportal.org](http://www.medicalhomeportal.org)

**MUMS (parent support):** [www.netnet.net/mums](http://www.netnet.net/mums)

**National Organization for Rare Disorders (NORD):** [www.rarediseases.org](http://www.rarediseases.org)

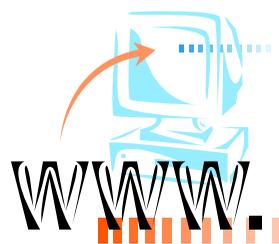
**Need to Know:** [www.ndcpd.org/n2k](http://www.ndcpd.org/n2k)

**ParentsPlace:** <http://parenting.ivillage.com>

**Social Security Administration:** [www.ssa.gov](http://www.ssa.gov)

**Starlight/Starbright Children's Foundation:** [www.starlight.org](http://www.starlight.org)

**University of Minnesota Children's Center:** [www.uofmchildrenshospital.org](http://www.uofmchildrenshospital.org)



### 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](http://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/](http://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](http://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.

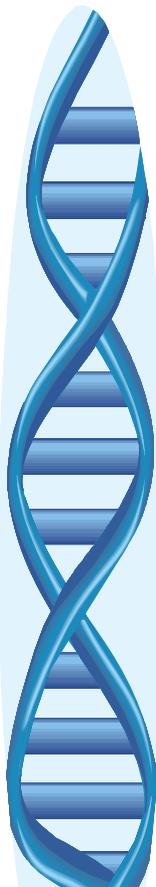
[www.ndhealth.gov/cshs/links.htm](http://www.ndhealth.gov/cshs/links.htm)

### 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](http://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/](http://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](http://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 Endocrinologist
- 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](http://www.ndhealth.gov/cshs/provider.htm)

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  
701.775.5577 or 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  
701.774.0741 or 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](http://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](http://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](http://www.ndhealth.gov/wic)



## 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](http://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](mailto: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](http://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](http://www.nd.gov/dhs/services/medicalserv/chip)



## 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](http://www.annecenter.org)

701 3<sup>rd</sup> Street NW

Jamestown, ND 58401

701.252.3850

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](http://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](http://www.nd.gov/dhs/locations/countysocialserv/index.html)
- North Dakota Integrated Services –  
[www.ndcpd.org/ndis](http://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](http://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](http://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](http://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](http://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](http://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



### **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](http://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](http://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](http://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.

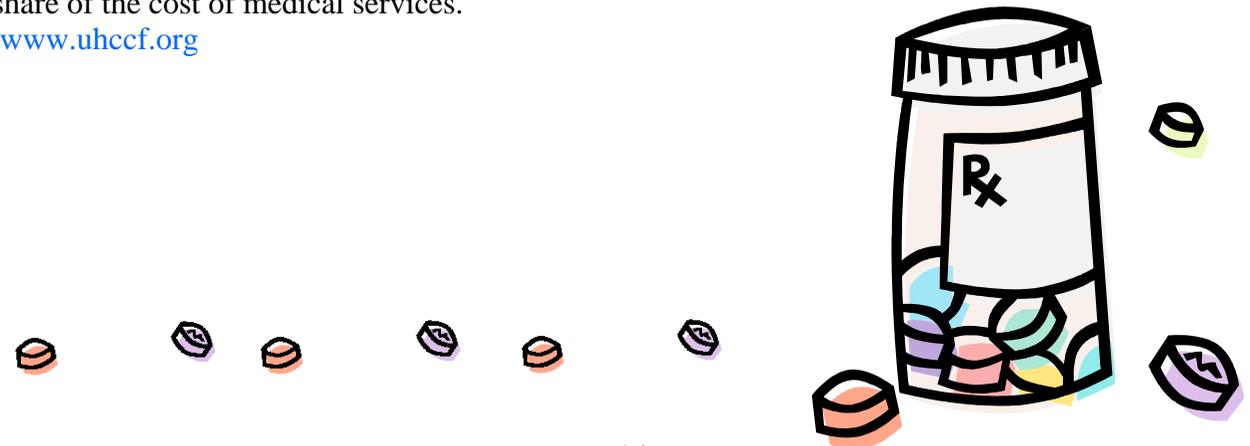
888.575.6611

[www.rxconnectnd.org](http://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](http://www.uhccf.org)





## 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](http://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](http://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](http://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](http://www.chand.org)

**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](http://www.nichcy.org)

### **Pathfinder Services of North Dakota, Inc.**

Family Training and Information Center  
1600 2<sup>nd</sup> 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](http://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](http://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](http://www.freedomrc.org/links.html)

### **Dakota Center for Independent Living**

311 East Broadway  
Bismarck, ND 58501  
701.222.3636 or 800.489.5013

### **Freedom Resource Center**

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

### **Options Interstate Resource Center**

318 3rd St NW  
East Grand Forks, MN 56721  
218.773.6100 or 800.726.3692

### **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. 7<sup>th</sup> Street, Bismarck, ND 58501 701.258.5076 [www.rmhcibismarck.com](http://www.rmhcibismarck.com)

**Fargo:** 1330 18<sup>th</sup> Ave South, Fargo, ND 58103 701.232.3980 [www.rmhc Fargo.org](http://www.rmhc Fargo.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](mailto: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](http://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](http://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](http://www.ndhealth.gov)

## Libraries

**North Dakota State Library** – 701.328.4622 or toll-free at 800.472.2104  
[www.library.nd.gov](http://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](http://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](http://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](http://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](http://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](http://www.dpi.state.nd.us)

## 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/](http://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](http://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](http://www.thearcuppervalley.com)

Valley City: The Arc of Barnes County  
700 11th Street NW #135  
Valley City, ND 58072  
701.845.5845



## 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](mailto: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](http://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](http://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/](http://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](http://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](http://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](http://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](http://www.shrinershq.org)

