BIRTH DEFECT RESEARCH FOR CHILDREN



How to find FINANCIAL ASSISTANCE?

Caring for a child with birth defects can be very challenging especially when there are also financial concerns. Every parent wants to ensure that their child receives the best medical care available. Unfortunately, far too many families do not have health insurance and cannot afford the medical care needed for a child with birth defects.

We hope that this fact sheet helps you find the necessary resources to care for your child and alleviates financial strain. There are many government programs, non-profit organizations and local service clubs that can help. Please review this fact sheet for a listing of government programs and non-profit organizations that provide assistance for children with various birth defects.



Where to start: You are likely to find the most financial assistance from the government .To find the government programs you may qualify for go to www.govbenefits. gov and fill out the questionnaire under the "Benefits" tab. The website will then give you a listing of all government programs for which you qualify. GovBenefits. gov is the official benefits website of the U.S. government, with information on over 1,000 benefit and assistance programs. Another helpful resource is the www.DisabilityInfo.gov website which connects you to the federal government's disability-related information and resources.

Below are some of the government programs that you will find at **www.govbenefits.gov**

Medicaid: The Medicaid Program provides medical benefits to low-income people who have no medical insurance or have inadequate medical insurance.

To find out whether your child is eligible to receive Medicaid benefits, contact your state Medicaid office. Phone numbers for each state office can be obtained through this website: http://cms.hhs.gov/contactcms/or for general information visit

http://www.cms.hhs.gov/home/medicaid.asp

Social Security: Social Security provides many benefit programs. For example, the Supplemental Security Income (SSI) program pays benefits to disabled adults and children who have limited income and resources.

To find out if your child may be eligible for any of the benefits SSA administers, visit http://best.ssa.gov or call Social Security's toll-free number: 800-772-1213. If you are hearing impaired, please call Social Security's toll-free TTY number: 800-325-0778

CHIP: The Children's Health Insurance Program is jointly financed by the Federal and State governments and is administered by the States. CHIP has allocated about \$20 billion over 10 years to help states insure low-income children who are ineligible for Medicaid but cannot afford private insurance.

For more information about this program, visit the **www.govbenefits.gov** website and enter the program name and your resident state into the search box or visit www.insurekidsnow.gov to be matched with a program in your state.

Assistance for Infants and Toddlers with Disabilities?

Early intervention services, including child find, evaluations and assessments, service coordination and the development and review of the Individualized Family Service Plan (IFSP), are available at no cost for eligible infants and toddlers with disabilities (birth to 3 years of age) and their families. Other early intervention services designed to meet the unique needs of the child may be provided on a fee-for-service or sliding fee scale on a state-by-state basis.

For more information about this program, please visit the **www.govbenefits.gov** website and enter the program name into the search box or link to the application page at **http://www.nectac.org/contact/ptccoord.asp**

Protection and Advocacy of Individual Rights

The Protection and Advocacy of Individual Rights program provides grants for states to support systems for protection and advocacy for the rights of individuals with disabilities who are ineligible for services from the Protection and Advocacy for Developmental Disabilities (PADD) program and the Protection and Advocacy for Individuals with Mental Illness (PAIMI) program, or whose problems fall outside the scope of services available from the Client Assistance Program (CAP).

For more information about this program, visit the www.govbenefits.gov website and enter the program name into the search box or link to the application page at http://www.ed.gov/programs/rsapair/applicant.html



Special Education – Grants to States

A free and appropriate public special education is available in all states for all eligible children and youth identified with disabilities under the Individuals with Disabilities Education Act (IDEA). Services are provided, at no cost to parents, primarily through their state's public school system.

For more information about this program, please visit the www.govbenefits.gov website and enter the program name into the search box or link to the application page at:

http://www.ed.gov/programs/osepgts/applicant.html

VA- Birth Defects Assistance – Health Care – Children of Women Vietnam Veterans Health Care Program

The program covers most health care services and supplies that are medically or psychologically necessary for the treatment of conditions related to the covered birth defect. VA can also reimburse expenses for travel to and from your doctor or health care facility.

For more information about this program, please visit the www.govbenefits.gov website and enter the program name into the search box or link to the application page at: http://www.va.gov/vaforms/and download form 21-0304.

To contact VA, please call: **1-800-827-1000**. People who are hearing impaired may call this toll-free TTY number: **1-800-829-4833**.

Children of Women Vietnam Veterans Monthly Monetary Allowance

Under Public Law 106-419, children born to women Vietnam veterans may be eligible for a monthly monetary allowance if they suffer from certain covered birth defects. VA identifies the birth defects as those that are associated with the service of the mother in Vietnam and resulted in permanent physical or mental disability. Level of disability will determine the monthly monetary amount.

To apply you must complete form VA Form 21-0304, Application for Benefits For Certain Children of

Vietnam Veterans with Disabilities. Link to the application page at: http://www.vba.va.gov/BLN/21/Topics/Women/Birth.htm

For more information call: 1-800-820-1756

VA – Birth Defects Assistance – Health Care – Spina Bifida Health Care Program

The program covers most health care services and supplies that are medically or psychologically necessary for the treatment of conditions related to spina bifida (other than spina bifida occulta). VA can also reimburse expenses for travel to and from your doctor or health care facility.

For more information about this program, please visit the **www.govbenefits.gov** website and enter the program name into the search box or link to the application page at **http://www.va.gov/vaforms/.** and download form 21-0304.

VA – Birth Defects Assistance – Payments for Children with Spina Bifida whose Parents Served in Vietnam or Korea

Spina Bifida patients who are natural children of Vietnam and Korea veterans may be eligible for a monthly monetary allowance.

For more information about this program, please visit the **www.govbenefits.gov** website and enter the program name into the search box (top right hand side of the website) or link to the application page at **http://www.va.gov/vaforms/**. and download form 21-0304

VA – Birth Defects Assistance Vocational Training for Children with Spina Bifida or Other Birth Defects

VA provides a Vocational Rehabilitation and Employment program for natural children diagnosed with spina bifida (other than spina bifida occulta) born to certain Vietnam veterans. This program enables a qualified child to prepare for and attain suitable employment. Services may include counseling and



rehabilitative services, education, training, and employment services. VA pays for the cost of these services.

For more information about this program, please visit the **www.govbenefits.gov** website and enter the program name into the search box or link to the application page at **http://www.va.gov/vaforms/**. and download form 21-0304

NON PROFIT/PRIVATE ASSISTANCE

HILL-BURTON FREE AND REDUCED COST HEALTH CARE

In 1946, Congress passed a law that gave hospitals, nursing homes and other health facilities grants and loans for construction and modernization. In return, they agreed to provide a reasonable volume of services to persons unable to pay and to make their services available to all persons residing in the facility's area. The program stopped providing funds in 1997, but about 200 health care facilities nationwide are still obligated to provide free or reduced-cost care.

For more information about the Hill-burton program and for a list of participating facilities please visit: www.hrsa.gov/hillburton/default.htm

Or call the Hill Burton Hotline: 1-800-638-0742 (1-800-492-0359 in Maryland)

SHRINERS HOSPITALS FOR CHILDREN

Shriners Hospitals for Children is an international health care system of 22 hospitals dedicated to improving the lives of children by providing specialty pediatric care, innovative research and outstanding teaching programs. Children up to the age of 18 with orthopaedic conditions, burns, spinal cord injuries and cleft lip and palate are eligible for admission and receive all care in a family-centered environment at no charge – regardless of financial need.

To contact Shriners Hospitals for Children, please call: **1-800-237-5055** or visit their website at **www.shrinershq.org**

LARRY KING CARDIAC FOUNDATION

The Larry King Cardiac Foundation (The LKCF) was established in 1988 to provide funding for life-saving treatment for individuals who, due to limited means and no insurance, would otherwise be unable to receive the treatment and care they so desperately need. The Foundation works in conjunction with hospitals throughout the nation to ensure that patients receive proper medical attention. Doctors performing these surgeries at no charge. Hospitals are compensated only for the materials used. Hearts are repaired. Families are given another chance. Lives are saved.

To contact The Larry King Cardiac Foundation, please call **1-866-302-5523** or visit their website at **www.lkcf.org**

THE AIR CARE ALLIANCE

Pilot volunteers from many public benefit flying organizations help hundreds of people each month by transporting needy patients to facilities where they are able to receive medical attention. Free air transportation is available to those who do not have insurance or other resources to cover commercial transport via air ambulance, charter, or airline. The public benefit fly when financial need or other special circumstances mean a compelling human need would go unfulfilled.

To contact The Air Care Alliance, please call **1-888-260-9707** or visit their website at **www.aircareall.org**

DISABLED CHILDREN'S RELIEF FUND

Disabled Children's Relief Fund (DCRF) provides disabled children with small grants to obtain wheelchairs, orthopedic braces, walkers, lifts, hearing aids, eyeglasses, medical equipment, physical therapy, and surgery. Children can be eligible for assistance if they have any of the following disabilities: vision or hearing loss, limb amputation, cerebral palsy, muscular dystrophy, spastic quadriplegia, encephalitis, rheumatoid arthritis, spina bifida, Down's Syndrome, and other disabilities. DCRF focuses special attention on

helping children throughout



the U.S. that do not have adequate health insurance, especially the physically challenged.

To contact DCRF, please call **516-377-1605** or visit their website at **www.dcrf.com**

THE EASTER SEALS DISABILITY SERVICES

Easter Seals Child Development Center Network is the largest provider of inclusive child care in the United States. Easter Seals Child Development Center Network assures that quality child care will be available to all children and their parents, regardless of ability. There are Easter Seals Child Development Centers in communities across the nation to help children of all abilities work toward developmental goals at the time in their lives when they are most ready to learn. Each Easter Seals facility offers ongoing training for staff; low adult to child ratios; developmentally appropriate learning activities; and top-quality facilities that meet or exceed industry standards. As a non-profit organization, Easter Seals provides its high-quality services at costs that are affordable to families in need.

To contact Easter Seal Disability Services directly, please call: **1-800-221-6827** or visit their website at **www.easterseals.com**

UNITED HEALTH CARE CHILDREN'S FOUNDATION

The United Health Care Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-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. This "support" is in the form of a grant to be used for medical services not covered or not completely covered by commercial health benefit plans.

To contact United Health Care Children's Foundation, please call **952-992-4459** or visit their website at **www.uhccf.org**

RONALD MCDONALD HOUSE

Ronald McDonald Houses around the world offer families a way to stay together near their child's treatment hospital in a comfortable homelike setting. Services include home cooked meals, private bedrooms and playrooms for children. Some locations may also offer special suites for children with suppressed immune systems, accredited education programs, recreational activities, non-clinical support services and/or sibling support services. Families are charged a minimal per night fee, but no family is ever turned away because they cannot pay.

To contact the Ronald McDonald House directly, please call: **630-623-7048** or visit their website at **http://www.rmhc.org**

What you can do on your own

Check with family members to see if they belong to a service club (like the Kiwanis, Lions or Civitans) that may help to raise funds for your child's medical needs. You may also want to contact your church and local hospitals to see if they offer any assistance to families with children who have medical/special needs. Hospital social workers are often a very good resource for locating your state's assistance programs and organizations. Another way to raise funds is to organize your own fund-raising event. It doesn't have to be a large-scale event. It could be something as simple as a barbeque with an admission fee. You can contact local merchants to get food and door prizes donated. Remember your family members and friends want to help but don't know how; a fundraising event is an easy way for them to contribute.

Fact Sheet by:

Birth Defect Research Children, Inc. www.birthdefects.org

