**DIAMOND BLACKFAN ANEMIA RESOURCES**

Information for people with Diamond Blackfan anemia (DBA), and their families.

**ORGANIZATIONS**

Daniella Maria Arturi Foundation (DMAF)
Provides financial support for the research of DBA, increases awareness of DBA among medical professionals and federal policy makers, and coordinates the Annual DBA International Scientific Consensus Conference.
http://www.dmaf.org

Diamond Blackfan Anemia Foundation
Funds medical research projects, provides emotional support to families affected by DBA, organizes DBA family meetings and publishes the DBA newsletter twice a year.
http://www.dbafoundation.org

Diamond Blackfan Anemia Registry of North America
Established in 1993 to improve the understanding of DBA patients and their families. The DBAR collects clinical data on DBA patients and their families and offers participation in research protocols.
http://www.dbar.org

**NATIONAL RESOURCE CENTERS**

Schneider Children’s Hospital
Adrianna Vlachos, MD
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
Head, Bone Marrow Failure Program
Director, Diamond Blackfan Anemia Registry
Hematology/Oncology
269-01 76th Avenue, Room 255
New Hyde Park, NY 11040
Phone: 718-470-3024
DBA Nurse Hotline:
1-877-DBA-NURSE (322-6877)

University of Texas Southwestern Medical Center
George Buchanan, MD
Professor of Pediatrics
Director, Division of Hematology-Oncology
Department of Pediatrics
5323 Harry Hines Boulevard
Dallas, TX 75390-9063
Phone: 214-456-2382

**WEB & E-MAIL-BASED SUPPORT GROUPS**

Blackfan@yahoogroups.com
An electronic family support group. Semi-moderated Web site and e-mail group for DBA parents and patients. To subscribe, e-mail: blackfansubscribe@yahoogroups.com or go to the website at:
http://health.groups.yahoo.com/group/blackfan

DBA21@yahoogroups.com
Semi-moderated Web site and e-mail group for adult patients only. To subscribe, e-mail: dba21-subscribe@yahoogroups.com or go to the website at:
http://health.groups.yahoo.com/group/dba21

**GOVERNMENT ORGANIZATIONS**

Centers for Disease Control and Prevention (CDC)
Division of Blood Disorders
National Center on Birth Defects and Developmental Disabilities
Phone: 800-CDC-INFO (800-232-4636)
http://www.cdc.gov/ncbddd/hbd/default.htm

For more information call:
1-877-DBA-NURSE
Living with DBA

National Institutes of Health (NIH)
National Heart, Lung, and Blood Institute
Health Information Center
Provides information and resources.
Phone: 301-592-8573
TTY: 240-629-3255
http://www.nhlbi.nih.gov

National Institutes of Health (NIH) Clinical Trials
National Heart, Lung, and Blood Institute
Medical care provided at no charge to patients who meet criteria for NIH clinical trials
Phone: 301-496-3841
E-mail: mussel@mail.nih.gov
http://www.cc.nih.gov

Blood Transfusion
National Library of Medicine
MedlinePlus
Information and resources.

Stem Cell Transplant
BMT InfoNet
Information and support for transplant patients and their families.
Phone: 1-847-433-3313
Toll-free: 1-888-597-7674
(during regular business hours)
E-mail at: help@bmtinфонet.org
http://www.bmtinфонet.org

National Bone Marrow Transplant Link
Helps patients, as well as their caregivers, families and the health care communities meet the many challenges of stem cell transplant by providing information and support services.
Phone: 1-800-LNK-BMT (800-546-5268)
or 248-358-1886
http://www.nbmtlink.org

National Marrow Donor Program (NMDP)
Provides a registry of potential volunteer stem cell donors, resources for patients and physicians, and conducts research.
Phone: 1-800-627-7692
Office of Patient Advocacy: 1-888-999-6743
http://www.marrow.org/index.html

Cancer
American Cancer Society
Publications on cancer, treatment options, patient care, and support groups.
Phone: 800-227-2345
http://www.cancer.org

National Cancer Institute
Etiologic Investigation of Cancer Susceptibility in Inherited Bone Marrow Failure Syndromes (IBMFS). This is a study of the epidemiology and natural history of DBA in patients and their families.
http://www.marrowfailure.cancer.gov

Rare Diseases
National Institutes of Health
Office of Rare Diseases
Information about rare diseases, including links to support groups.
http://www.rarediseases.info.nih.gov

National Organization for Rare Disorders (NORD)
Information and patient networking.
Phone: 800-999-6673 or 203-744-0100
Email: ORPHAN@rarediseases.org
http://www.rarediseases.org

Health Insurance
Medicaid Health Insurance
Medicaid health insurance provides health care coverage for some people who cannot afford it.
http://www.cms.hhs.gov/home/medicaid.asp

COBRA Health Insurance
COBRA provides certain people with temporary continuation of health coverage at group rates.
http://www.dol.gov/ebsa/fags/faq_consumer_cobra.html

Other Resources
Camp Sunshine
Its mission is to address the impact of life-threatening or chronic illness on every member of the family.
Phone: 207-655-3800
http://www.campsunshine.org