What is Diamond Blackfan Anemia?
Diamond Blackfan Anemia (DBA) is a rare blood disorder. In DBA, the bone marrow (the center of the bone where blood cells are made) does not make enough red blood cells that carry oxygen throughout the body.

What causes DBA?
DBA is usually diagnosed during the first year of life. Some people have a family history of the disorder. About one-quarter of people with DBA have a known genetic cause. In many people with DBA, we do not know the cause.

How many people have DBA?
There are about 25-35 new cases of DBA per year in the United States and Canada.

Can anyone have DBA?
DBA affects both boys and girls equally. It occurs in every ethnic group.

Can other family members have DBA?
Yes, if you have DBA there is up to a 50 percent chance that each of your children will have DBA. Symptoms can be very mild to very severe.

Where did DBA get its name?
The anemia was named for Dr. Louis K. Diamond and Dr. Kenneth D. Blackfan, the first doctors who documented cases of the disease in the 1930s.

What are the signs and symptoms of DBA?
People with DBA have symptoms common to all other types of anemia, including pale skin, sleepiness, rapid heartbeat, and heart murmurs. In some cases there are no obvious physical signs of DBA. About one-quarter of people with DBA have abnormal features involving the face, head, and hands, especially the thumbs. They may also have heart and kidney defects. Many children are short for their age and may start puberty later than normal.
How do doctors know if someone has DBA?
Several tests may be used to tell if a person has DBA. One test your doctor can perform is called a bone marrow aspirate. This is where a needle is inserted into the bone and a small amount of bone marrow fluid is taken out and studied under a microscope. You may also have blood tests to see if there is a genetic basis for DBA or certain chemical abnormalities linked to DBA.

Will iron help reduce the anemia?
No. DBA is not caused by a lack of iron or other nutrients.

How is DBA treated?
To treat very low red blood cell counts in DBA patients, the two common options for treating DBA are corticosteroids and blood transfusions. Bone marrow/stem cell transplantation may also be considered. Some children need no specific therapy. Your doctor will recommend the best treatment for you.

What is corticosteroid treatment?
Corticosteroids are drugs used to treat many medical conditions. One type of corticosteroid is called oral prednisone, one of the most successful treatments for children with DBA.

What are the side effects of corticosteroid treatment?
Major side effects when these drugs are used in high doses for a long time include weight gain, water and salt retention, high blood pressure, muscle weakness, osteoporosis (brittle bones occasionally leading to fractures), wounds that won’t heal, headaches, growth problems, eye diseases such as cataracts and glaucoma, and the disruption of hormones that regulate normal body functions, including diabetes. Patients on these drugs should be watched carefully.

What is a blood transfusion?
In a blood transfusion, a person receives healthy red blood cells from another person. Transfusions may be needed every 3-5 weeks.
Do blood transfusions have any complications?
Sometimes patients can develop transfusion reactions with fever and rash. Medication may be given before the next transfusion to help prevent these symptoms. Red cell transfusions can also cause a build-up of extra iron in the body which can harm the heart and/or liver, cause diabetes, or slow down normal growth. The amount of iron must be regularly checked. If iron levels are too high, your doctor may recommend drugs to remove excess iron in body tissues. This process is called chelation therapy. People getting transfusions should avoid iron supplements.

What is bone marrow/stem cell transplantation?
Bone marrow/stem cell transplantation replaces a patient’s bone marrow/stem cells with those from a healthy, matching donor.

Are there other treatment options for DBA?
Other treatment options are being studied but to date none work as well as corticosteroids or transfusion therapy. The goal is to one day find a safe, reliable cure, possibly using gene therapy. But this is still many years away.

Who can I call with questions?
For answers to your immediate medical questions, call the DBA nurse, Ellen Muir, RN, MSN, at 1 (877) DBA-NURSE. To talk to a parent of children with DBA, call the DBA Foundation at (716) 674-2818.
Foundations
Diamond Blackfan Anemia Foundation (DBAF)
Funds medical research projects, provides emotional support to families affected by DBA, organizes DBA family meetings, and publishes the DBA Newsletter twice a year.
P. O. Box 1092
West Seneca, New York 14224
Main Number: (716) 674-2818
http://www.dbafoundation.org/

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.
P. O. Box 2022
Remsenburg, NY 11960
http://www.dmaf.org/

Registry
Diamond Blackfan Anemia Registry of North America (DBAR)
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.
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http://www.dbar.org/

DBA National Resource Centers
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Web and E-mail-based Support Groups
Blackfan, An Electronic Family Support Group
Blackfan@yahoogroups.com
An e-mail server that allows you to send one e-mail that automatically gets distributed to everyone subscribed to the list. This is a semi-moderated web site and e-mail group for DBA parents and patients. To subscribe, e-mail: blackfan-subscribe@yahoogroups.com, or go to the web site at: http://health.groups.yahoo.com/group/blackfan/.

DBA21@yahoogroups.com
This is a semi-moderated web site and e-mail group for adult patients only. To subscribe, e-mail: dba21-subscribe@yahoogroups.com or go to the web site at: http://health.groups.yahoo.com/group/dba21/.

Centers for Disease Control and Prevention (CDC)
Sally Owens, BSN, RN
Health Scientist, Division of Hereditary Blood Disorders
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention
1600 Clifton Road, MS E 64
Atlanta, GA 30333
Main Number: 800-CDC-INFO (800-232-4636)
http://www.cdc.gov/ncbddd/hbd/default.htm

Other Resources
Camp Sunshine
Its mission is to address the impact of life threatening or chronic illness on every member of the family.
35 Acadia Rd
Casco, ME 04015
Main Number: (207) 655-3800
http://www.campsunshine.org/