

TYPES OF DOCTORS AND OTHER PROVIDERS ON THE MEDICAL TEAM

Information for people with Diamond Blackfan Anemia, and their families.

Diamond Blackfan Anemia (DBA) is an uncommon blood disorder that can affect many parts of the body. In addition to a primary care provider, a person with DBA may need to see other medical specialists. Recommendations for follow-up care depend on the treatment one gets for DBA. Please see the Corticosteroid Therapy fact sheet and the Blood Transfusion Therapy fact sheet for more information (<http://www.cdc.gov/ncbddd/hbd/dba/treatment.htm>). Following is an overview of doctors and other medical professionals who might provide care for people with DBA.

Primary Care Provider

A primary care provider may be a family doctor, pediatrician, internist, physician's assistant, or nurse practitioner. This person takes care of regular health care needs. This doctor also makes referrals to specialists when necessary. Together these health specialists should monitor the following:

- Height and weight every few months.
- Physical exams and vital signs.
- Complete blood count (CBC) and blood chemistry results.
- Hormone levels.
- Kidney function.
- Possible heart problems.
- Bone density.
- Bone age.
- General health and development through periodic developmental screening (vision and hearing, scoliosis, checks on school growth and development).

When should a person with DBA see a primary care provider?

- Regular health exams.
- Well-child checks.
- Minor illnesses, injuries, and treatment of other medical conditions.
- Vaccinations (shots).
- Fever of 101.5° F or higher.
- During or after a viral illness, if pale or feeling weak.

If your child is exposed to an infectious disease, such as chicken pox or parvovirus, you should call your provider for instructions. Parvovirus usually causes fifth disease. Symptoms of fifth disease typically include a fever with a slapped-cheek rash on the face and a lacy red rash on the trunk, arms, and legs. Parvovirus can also temporarily interfere with the body's ability to make red blood cells. Chicken pox and parvovirus can potentially have more serious health consequences in DBA patients that may require extra precautions.

Hematologist

A hematologist is a doctor who specializes in blood diseases. The hematologist works with the primary care provider to help diagnose and manage treatments for DBA. The hematologist

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and other specialists will also help manage and monitor the side effects of treatments. The hematologist may also coordinate or recommend heart and kidney ultrasound tests to screen for birth defects.

When should a person with DBA see a hematologist?

- As soon as possible after diagnosis, to develop a customized treatment plan.
- For questions regarding precautions, complications, and treatment options of DBA.
- Based on the patient's needs, the hematologist may be seen monthly or at least annually.

A hematologist's expertise in blood and in DBA treatments make him or her a vital member of the DBA medical team. Your hematologist should be informed of, and consulted with, any medical change or concern.

Endocrinologist

An endocrinologist is a doctor who specializes in the endocrine system, which is made up of glands that release hormones. These glands help control how people grow and develop, and they may be affected by certain treatments for DBA.

When should a person with DBA see an endocrinologist?

- Children who have slow growth or are small for their age.
- Those taking steroid medicine long-term (more than 3 months) or having frequent blood transfusion therapy.
- If hormone levels are not normal.

Nephrologist or Urologist

A nephrologist is a doctor who specializes in kidneys. A urologist is a doctor who specializes in the urinary system. Some people with DBA have problems with their kidneys or urinary system. A nephrologist or urologist can recommend a treatment or a monitoring plan, if needed.

When should a person with DBA see a nephrologist or urologist?

- The primary care provider can order an ultrasound (a test that uses sound waves to look inside the body) to check the kidneys and urinary system. If the test results are not normal, the primary care provider or hematologist should make a referral to a nephrologist or urologist.

Cardiologist

A cardiologist is a doctor who specializes in the heart. Because people with DBA have a low number of red blood cells, the heart has to work harder, causing it to become larger than normal. In addition, a person having blood transfusion therapy may have extra iron in the heart, which could result in heart failure.

When should a person with DBA see a cardiologist?

- The primary care provider can order a test called an echocardiogram (also called echo) every 2 or 3 years. For those having blood transfusion therapy, an echo might be done more often. Echo is a test that uses sound waves to look at the heart. If the results are not normal, the primary care provider may make a referral to a cardiologist. The results of the echo and advice of the cardiologist should also be shared with the hematologist.

Ophthalmologist

An ophthalmologist is a doctor who specializes in the eye. Because of medical treatment for DBA, people with DBA may be more likely to have certain eye problems, including glaucoma (increased pressure in the eye), strabismus (lazy eye), or cataracts (cloudiness of the lens of the eye).

When should a person with DBA see an ophthalmologist?

- Because eye problems can lead to vision loss if not treated, people with DBA should see an ophthalmologist on a regular basis.



- Some medications and treatments used for DBA may also affect vision. All people having chelation therapy (treatment to remove excess iron from the body) or taking steroids such as prednisone should see an ophthalmologist.

Audiologist

An audiologist is a professional who specializes in hearing problems. Some treatments and medications used for DBA may cause hearing loss.

When should a person with DBA see an audiologist?

- All DBA patients requiring chelation therapy should be evaluated by an audiologist prior to starting chelation and at least once per year during chelation therapy.

Nurse/Nurse Practitioner

A nurse is a health care professional who is trained to provide medical care and prevention services to eliminate or reduce complications. Some primary care physicians and specialists have nurses or nurse practitioners to assist their patients in coordinating their care and answering their medical questions.

When should a person with DBA see or call a nurse?

- For medical questions.
- To further explain tests or treatments.

Family/Social Support Services

Dealing with the diagnosis, or the duration of a chronic illness, may at times become difficult. Many support services are available to help families (social workers, psychologists, counselors, child life specialists).

Important Things to Remember

- Ask questions until you understand the answers. Make a list ahead of time to discuss with your doctors at the next visit.
- Be your own advocate because many doctors are not familiar with DBA. Search for doctors that are willing to stay abreast of new treatments and technologies. Do your homework and be part of the decision-making process.
- Take responsibility for maintaining your own health records by using the forms from Managing Your DBA Care: A Notebook for Families, available at <http://www.cdc.gov/ncbddd/hbd/dba/default.htm>, as a guideline for your care.
- Consider carrying or wearing a medical identification card, bracelet, or necklace.
- Be aware of safety precautions, such as handwashing, proper medication and dosing, and the potential for human error while in a health care setting.
- Consider informing the school nurse or human resource department of special circumstances you might have.
- Notice how you are feeling and let the doctors know about any changes in your health, such as feeling more tired than usual. Check in with the doctors regularly to let them know how you are doing. Let them know if you are having trouble following your treatment plan. They can help you make changes in the plan if it is not working for you.
- Ask for help. Support can come from friends, family members, counselors, doctors and nurses on your medical team, or a support group for people with DBA.
- Every member of the DBA medical team is important. To ensure that you are receiving the best possible medical care, make sure that your doctors are in communication with each other.
- Stay positive! Remember, you are not alone. There are hundreds of others around the world, just like you, living with DBA.