

MANAGING YOUR DBA CARE: A NOTEBOOK FOR FAMILIES

Building a notebook to manage your DBA care

Whether you have Diamond Blackfan Anemia (DBA) or you have a child with DBA, creating a notebook to manage your DBA care is a good idea. This fact sheet describes:

- Why it is important for you to create a notebook to manage your DBA care.
- How to put together your notebook.
- What forms to include in your notebook and how you can print them out at home.
- Who should know about your notebook.
- How often you should update the information in your notebook.

This fact sheet gives ideas about what you could track. However, you should sit down with your doctor or nurse and talk about what types of information would be best for you to collect.

Why should I create a DBA Care Notebook?

Since many doctors are not familiar with DBA it is very important for you to take an active role in managing your own, or your child's, care. To make important decisions you need to know about DBA, understand your treatment options, and then make the best possible choices for your health or the health of your child. Putting together a DBA Care Notebook that you can take with you wherever and whenever (doctor's appointments, vacation) you need it will help you:

- Organize all of your DBA-related medical information in one place so that you can keep track of information over time. You may want to collect the following:
 - Doctor's contact information.
 - Medical appointments.
 - Changes in medications, treatments, or transfusions.
 - Test results.
 - Vaccinations (shots).
 - Allergies or harmful reactions.
 - Any other information about your condition (facts found on the Internet, brochures, and other sources of information and support).
- Save time by not having to search around the house for loose papers before you leave for a doctor's visit.
- Actively take part in, and advocate for, your own or your child's care.
- Work together with the doctors on the DBA medical team.
- Talk about your condition with doctors or nurses when you are away from home, on vacation, or moving to a new community.
- Remember new and complex information that is hard to process (when the doctor first tells you about the condition, when the condition worsens, or when treatment changes).
- Begin to take responsibility for your own health history and information if you are a teenager or young adult with DBA.

For more information call:

1-877-DBA-NURSE





How do I build a DBA Care Notebook?

It's simple. All you need is a large 3-ring binder (at least 2 inches wide) with pocket dividers or colored tabs and a 3-hole punch. You may want to include plastic pages. These pages can hold business cards or other materials that cannot easily be 3-hole punched. You should design your notebook to meet your specific needs. However, it is a good idea to have a divider in the notebook for each of the following topics, in the following order:

- **Contact information for the DBA medical team**—This list should be right up front. It will help you keep track of the many different doctors and nurses you or your child might need to see. You should include contact information for the person(s) to call in case of an emergency, your insurance company, and the following health care professionals:
 - Primary care provider.
 - Hematologist (a doctor that specializes in blood diseases).
 - Endocrinologist (a doctor who specializes in the endocrine system, which is made up of glands that release hormones).
 - Cardiologist (a doctor who specializes in the heart).
 - Nephrologist (a doctor who specializes in kidneys)
 - Urologist (a doctor who specializes in the urinary system).
 - Ophthalmologist (a doctor who specializes in the eye).
 - Audiologist (a doctor who specializes in hearing problems).
 - Dentist.
 - Family/social support services (social workers, psychologists, counselors, child life specialists).

You may see some of these providers only one time. Others you may visit more often. Keeping an updated record of your medical team's information will keep you from having to look up their numbers over and over again. It will also help your medical team work together to keep track of how you are doing.

- **Doctor visits and hospital stays**—This list should come right after your doctor's contact information. You should create a record of your medical history. You will want to record who you or your child has seen, when and why, as well as when the next visit is scheduled to take place. You should also write down if you or your child has had any surgeries or had to stay overnight in the hospital for any reason.
- **Growth chart**—During each checkup, your doctor will measure your child's height, weight, and the size of his or her head. The doctor can then compare your child's measurements to those from a chart of national averages for children of the same age and gender. You can also track these measurements at home. These measurements are merely guides for a doctor to help in assessing your child's growth. They can, however, be useful in signaling possible developmental problems.
- **Medication log sheet**—This list should include:
 - The names of the medicines.
 - Why you take them.
 - Who prescribed them.
 - How much of them to take (dose).
 - How often to take them (frequency).
 - When you first started taking them and when, if at all, you stopped taking them.
 - Allergies you may have (especially drug allergies).
 - Bad allergic reactions to past medications, along with the side effects.
 - The name and number of your pharmacy.



In addition, you should list information related to your medical equipment, such as needle size gauge numbers, or serial numbers, on this form.

- **Lab test results**—It's a good idea to get a copy of all your lab test results and procedures, whether it's a routine blood test or a test taken because of your DBA. You do not have to track this information by using the form provided if you don't want to. Instead, you can just insert a copy of the lab results into this section of your binder. Keep the most recent test results in front of the older ones so that it will be easier to find the most current information.
- **Transfusion log sheet**—Keeping track of your transfusions is no different than keeping track of all of your other medical reports and prescriptions. You should record your transfusion requirements, premedication needs, the date of your transfusion, number of units/volume (mL/kg) transfused, and the number of days or weeks since your last transfusion. You may also want to track your pretransfusion hemoglobin level, ferritin level (amount of stored iron in the body), and chelation status.
- **Vaccination log**—This log helps you and your doctor make sure your child gets his or her shots on schedule. If you move or change doctors, having an accurate record might prevent your child from having shots he or she has already had. A record should be started when your child receives his or her first shot and updated with each visit.
- **Notes pages**—Include blank pages to jot down notes during your doctor's visits or when you are getting advice over the telephone. These notes can be anything from general medical advice to new prescriptions. You may even want to write down the steps you need to take to stick to the treatment your doctor has recommended. You can also use the notes pages to write down questions that you want to be sure to bring up at your next appointment. This way you won't have to worry about forgetting something important.
- **Other**—There are many different ways to organize your DBA Care Notebook. Set it up the way that makes the most sense to you. You may choose to include a few more sections in your binder for other important information. Examples might include copies of letters your doctors send to other doctors or insurance companies, medical billing information, insurance papers, and information you have researched about your condition. You may wish to include a calendar to schedule and keep track of appointments. Leave a few extra dividers in the notebook at the back so that you can easily add new sections when needed.

Where can I find and print the forms for my DBA Care Notebook?

You can print copies of these forms, which are available at <http://www.cdc.gov/ncbddd/hbd/dba/default.htm>. The Centers for Disease Control and Prevention, parents of children with DBA who have years of experience monitoring their child's care, and nurses from DBA National Resource Centers developed the forms listed above.

Who should know about my DBA Care Notebook?

You should make sure that a family member or other caregiver knows that you have a DBA Care Notebook. You should also make sure that they can find it in an emergency and bring it to the clinic or hospital where you are receiving care.

How often should I update the information in my DBA Care Notebook?

To be the most helpful, your DBA Care Notebook needs to provide a snapshot of your current health status. Keep your medical records up-to-date. Be sure to include new prescriptions and treatment information. Once every few months, you might want to go through your notebook and remove or file certain sections if they are getting too large or find you no longer need them.