

Diamond Blackfan Anemia Registry
Feinstein Institutes for Medical Research
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Dear Patient/Parent of Patient with DBA:

As you know Diamond Blackfan anemia (DBA) is a rare inherited bone marrow failure syndrome that is characterized by anemia, birth defects, poor linear growth and a predisposition to certain cancers. Based upon our analyses of data from the DBAR we are recommending screening for colorectal cancer in individuals with DBA. Our two previous analyses from the Diamond Blackfan Anemia Registry reveal that individuals with DBA have a 4.8-fold higher risk of developing cancer with an overall incidence of 13.7% by age 45 years. The two most prevalent solid tumors are colorectal cancer and osteogenic sarcoma. The incidence of colorectal cancer in DBA, beginning at age 20 years, is in the range observed in non-DBA affected adults beginning at an age of 45 years. In those individuals, colonoscopy has been able to detect pre-cancerous adenomas and early cancer. Early detection has reduced the amount of therapy required and has dramatically improved outcomes. We expect this to be true for individuals with DBA. Thus our data support the institution of colonoscopy for colorectal cancer screening and surveillance in individuals with DBA beginning at 20 years of age. The results of the initial colonoscopy will determine the interval between repeat evaluations. Further analysis is ongoing to determine if early screening for osteogenic sarcoma or other cancers is warranted. Our findings and recommendations have been published.

If you have any questions or find you are having trouble obtaining insurance approval for a colonoscopy please feel free to contact the Registry. Adrianna Vlachos, MD or Jeffrey M Lipton, MD, PhD can be reached toll-free at: (888) 884-DBAR.

Sincerely,
The DBA Registry