Summer 2002

DBA Newsletter

Volume 6, Number 3 • When we all work together, anything is possible!

NCI Study Launched on Rare Inherited Bone Marrow Failure Disorders and Cancer Risk

The National Cancer Institute (NCI) is launching the largest North American study of its kind to focus on people with rare inherited bone marrow failure syndromes (IBMFS) and their immediate family members. This study, called the "NCI IBMFS Cohort," will follow families over a long period of time, and will examine the underlying genetic disorders of those diagnosed with IBMFS and their families, and analyze how certain factors can affect the course of these syndromes. Families with these disorders are invited to become part of the study, since they may be at a higher risk of cancer. These families can include previously or newly-diagnosed, affected individuals and their immediate family members, as well as surviving relatives (in families where the patient may have passed away) who may be carriers of one of the altered genes related to these diseases.

IBMFS, most often diagnosed during childhood, are relatively rare disorders that involve some form of aplastic anemia (where the bone marrow fails to produce blood cells). People with these syndromes are at increased risk of cancer such as leukemia or various specific solid tumors. The study includes family members since they, too, may be at increased risk of cancer.

The study will enroll families in which at least one member has or had an IBMFS such as:

- Fanconi's Anemia (FA)
- Diamond-Blackfan Anemia
- Shwachman-Diamond Syndrome
- Dyskeratosis congenita
- Severe congenital neutropenia
- Thrombocytopenia absent radii
- Amegakaryocytic thrombocytopenia
- Pearson's Syndrome
- Bone marrow failure other than acquired

The problem for families living with these conditions is the impending threat of cancer in young patients, without knowing whether it will happen or when it will happen. The challenge for researchers is understanding why cancer develops in so many people with IBMFS, why it occurs earlier than in the general population, and what the role is of IBMFS genes in carcinogenesis.

"By looking at a large group of patients and family members who may be cancer-prone, we hope to learn more about these issues, and to evaluate techniques for cancer screening and prevention in this particular group," comments Blanche Alter, M.D., M.P.H., the principal investigator at NCI. Alter

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Please submit pictures and articles, including Kid's Page information, for the next DBA Newsletter to the DBAF by September 30, 2002.

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has teamed with a large number of associate investigators in all specialties at the National Institutes of Health and at several extramural medical centers, in order to provide a truly comprehensive evaluation to persons with these complex, multi-system disorders.

The investigators hope to enroll all North American families with these syndromes. There will be two subgroups -- those who are seen and evaluated at the NIH Clinical Center in Bethesda, Maryland (called the "Clinical Center Cohort") and those who provide medical information but are not seen at the Clinical Center (called the "Field Cohort").

Affected individuals and their immediate family members who come to the Clinical Center will receive comprehensive physical and laboratory examinations by a team of specialists, along with information and advice regarding the management of any newly identified clinical problems that are detected during the course of their visit. Due to the high risk of cancers in this cohort, participants will be offered age-appropriate, thorough cancer surveillance as part of the study. At the participants' request, they will be given the results of clinical tests and cancer screening. The study will not provide treatment at the NIH; patients will be referred to their physicians for consideration of any treatments that may be necessary.

For further information about the study: "Etiologic Investigation of Cancer Susceptibility in Inherited Bone Marrow Failure Syndromes (IBMFS)," interested individuals may call 1-800-518-8474 to speak to Lisa Leathwood, the study's research nurse, or send an email to lisaleathwood@westat.com. More information is also provided on the study Web site at http://www.marrowfailure.cancer.gov. ■

TRANSFUSION AND CHELATION THERAPY IN DBA

by Howard A. Pearson, M.D., Professor of Pediatrics
Yale University School of Medicine

Diamond-Blackfan Anemia, also called Congenital Hypoplastic Anemia, and in England, Erythrogenesis Imperfecta, is an uncommon congenital anemia in which the bone marrow of the patient cannot produce red blood cells (RBC). The failure to produce RBC results in severe anemia in the first year of life. Without treatment, DBA can be fatal in infancy. In the 1950's, it was recognized that patients with DBA can be successfully treated with corticosteroids (prednisone) and many that respond can maintain normal levels of hemoglobin for long periods of time using quite small doses of prednisone. However, 30–40 % of DBA patients do not respond to prednisone therapy and must receive regular RBC transfusions to survive.

TRANSFUSION THERAPY:

Transfusion-dependent DBA children must receive about 15 ml of RBC per kilogram of body weight every 3 to 5 weeks in order to maintain their hemoglobin above 8–9 gm/dL. This hemoglobin level permits normal activity, growth and development in most children.

In the United States, almost all blood used for transfusion is obtained from healthy volunteer donors, and is subjected to a wide battery of tests to prevent diseases that can transmitted by blood transfusion. These include hepatitis B and C, and HIV/AIDS. Just before each transfusion, the RBC of the donor are carefully tested (cross-matched) against the patient's blood to prevent transfusion reactions. Because of these precautions, blood transfusions in the United States today are very safe, and transfusion reactions or transmission of blood-born diseases are very unusual. Studies are in progress that may make the blood supply even safer. A system is currently being tested that neutralizes the DNA or RNA of any infectious agents that may be present in the blood. This system could theoretically prevent transmission of viruses such as hepatitis and HIV as well as currently unknown viruses that might enter the blood supply in the future.

IRON OVERLOAD

Patients who must receive regular RBC transfusions over an extended period of time inevitably develop an excess of iron in their bodies (transfusional hemosiderosis). This is because the RBC has a red, iron-containing protein called hemoglobin that is necessary for transporting oxygen from the lungs throughout the body. After RBC are transfused, they have a limited survival. They survive for only about 40–50 days after which they are removed from the circulation. The RBC hemoglobin is then metabolized and its iron is retained in the body. Each unit of transfused RBC (about 250 ml) contains about 200 mg of iron, which is ultimately deposited in the tissues. Unfortunately, the body has no normal, physiological mechanism to excrete iron; so, with continuing RBC transfusions, body iron increases greatly. Chronically high levels of body iron can ultimately damage many

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tissues and organs. Iron damage to the endocrine glands may cause poor growth, delay of puberty and diabetes. Iron damage to the liver may cause cirrhosis. Iron damage to the heart may result in heart failure, irregularities of the cardiac rhythm and death.

Much of our understanding about transfusional hemosiderosis comes from patients with Thalassemia Major, another form of chronic, transfusion dependent anemia of children. In the past, most of these patients died in the second and third decade of life from the complications of transfusional hemosiderosis. It is likely that the prognosis of transfusion dependent patients with DBA would be similar unless transfusional hemosiderosis can be prevented.

IRON CHELATION THERAPY

There are a number of drugs that have the ability to combine with (chelate) body iron and facilitate its excretion. The only iron-chelating agent currently approved for use in the United States is deferoxamine mesylate (Desferal). Desferal is manufactured in the United States by Novartis Pharmaceuticals of Summit, New Jersey. Desferal is a nearly specific chelator of iron and does not remove other trace metals from the body. Unfortunately, Desferal is not effective when taken by mouth and it must be given by subcutaneous or intravenous injection. When injected into the body, Desferal combines with iron and the Desferal-iron complex is excreted in the urine, giving the urine a red color. After injection, Desferal is cleared from the circulation very rapidly (30–60 minutes). To be effective, it must be injected over an extended period of time – usually 10–12 hours, and this can be accomplished by the use of small, battery driven pumps. Most patients infuse 40–50 mg/kg of Desferal dissolved in 10–12 cc of sterile water through a small needle inserted under the skin of the abdomen or thigh each night while sleeping, and most patients try to do this 5 to 6 nights a week. There are a variety of pump systems. Many patients employ a home health service company to provide their pump, supplies and medication.

When Desferal is used in this fashion, it is possible to attain negative iron balance in most patients. This means that more iron is being removed than is being delivered into the body by the continuing RBC transfusions. Body iron can be estimated and monitored by periodic measurements of serum ferritin levels. With effective Desferal chelation therapy the serum ferritin can be kept below 1,500 mcg/dL – a level that is considered relatively safe with respect to preventing organ damage. Some centers recommend periodic liver biopsies to directly measure the amount of iron in the tissues.

Desferal therapy is safe and effective for the treatment of transfusional hemosiderosis. Patients with thalassemia major who are treated with Desferal have better survival and less organ damage. Severe side effects such as hearing loss and bone disease are unusual but these are periodically monitored.

Some patients develop hard, painful "lumps" at the site of the subcutaneous injections, and when these become frequent and debilitating, permanent, implanted venous access devices (Portocath) are sometimes indicated.

The Desferal protocol is difficult for many patients to follow, involving as it does considerable discomfort and inconvenience. It is also very expensive and must be continued as long as the patient is RBC transfusion dependent. It is not surprising that non-adherence to the treatment is quite common.

ORAL IRON CHELATES

Deferiprone (L-1) is an oral iron-chelating agent that is manufactured by Apotex, LTD, a Canadian pharmaceutical firm. Deferiprone has been studied in Europe and Canada. While it does increase iron excretion, it is not as effective as Desferal. One report described what was considered to represent possible liver fibrosis associated with Deferiprone use. Largely because of this, Deferiprone has not been licensed for use in the United States and Canada. It is, however, widely used in Europe and India. A more recent, and much larger international, multi-institutional study of patients receiving Deferiprone did not show an association with hepatic fibrosis. It is possible that the Food and Drug Administration may sometime in the future approve its use, particularly in iron-overloaded patients who are unable to use Desferal.

A drug designated as " ICL 670" also manufactured by Novartis Pharmaceuticals has recently undergone a so-called Phase 1 study. Phase 1 studies are done to assess drug metabolism and safety. If the results of the Phase 1 studies are encouraging, larger Phase 2 studies that assess effectiveness may be done. Phase 2 studies of ICL 670 are currently beginning in Europe.

The National Heart Lung and Blood Institute of the National Institutes of Health has made the development of new and more effective iron-chelating drugs a priority and has awarded a number of research grants for this purpose. A few other oral iron-chelating agents are in the "pipe line", but they will need much more study to confirm efficacy and safety before they can be considered for clinical use.

One of the major reasons for the relatively slow development and testing of iron-chelating agents by commercial pharmaceutical firms is that the market for and hence profit of these and other drugs used to treat so called "orphan diseases" is too limited to encourage the investment of the considerable amount of money necessary to develop and test new drugs. ■

DBA RESEARCH ARTICLES 2001

The following list includes many of the DBA research articles published during the year 2001. Available abstracts can be found at: www.ncbi.nlm.nih.gov/pubmed. Articles may be obtained from your local medical library or physician.

- **A new autosomal recessive syndrome. Early onset of pancytopenia, distinct facial features, growth retardation and developmental delay.**

  Al-Batniji FS, Mahmoud MA, Van Dijken PJ, Al-Asiri RH, Al-Swaid AF, Al-Marshedy AM.

  Saudi Med J. 2001 Dec;22(12);1122-6.

  PMID: 11802189

- **Clinical significance and interpretation of red cell enzyme analyses.**

  Kanno H. Fujii H.
  Rinsho Byori. 2001 Nov;Suppl 116:139-47. Review. Japanese.

  PMID: 11797375

- **Human herpesvirus 6 limbic encephalitis after stem cell transplantation.**

  Wainwright MS, Martin PL, Morse RP, Lacaze M. Provenzale JM, Coleman RE, Morgan MA, Hulette C, Kurtzberg J, Bushnell C, Epstein L, Lewis DV.
  Ann Neurol. 2001 Nov;50(5):612-9.

  PMID: 11706967

- **The Diamond Blackfan Anemia Registry: tool for investigating the epidemiology and biology of Diamond-Blackfan anemia.**

  The Diamond Blackfan Anemia Registry of North America (DBAR) is designed to study the epidemiology and biology of DBA. To date, 354 patients have been enrolled in the DBAR. Using this database, important epidemiological, clinical and laboratory observations have been made with regard to the clinical presentation, the inheritance of DBA, the genetics of congenital malformations, the therapeutic outcome, including the efficacy of hematopoietic stem cell transplantation, and the recognition of DBA as a cancer predisposition syndrome. In particular, the database is an essential substrate for DBA gene discovery. This article reviews the findings of the DBAR since its inception.

  Vlachos A, Klein GW, Lipton JM.

  J Pediatr Hematol Oncol. 2001 Aug-Sep;23(6):377-82. Review.

  PMID: 11563775

- **Oral megadose methylprednisolone therapy for refractory Diamond-Blackfan anemia. International Diamond-Blackfan Anemia Study Group.**

  Buchanan GR.

  J Pediatr Hematol Oncol. 2001 Aug-Sep;23(6):353-6.

  PMID: 11563769

- **Bilateral microtia and cleft palate in cousins with Diamond-Blackfan anemia.**

  This article discusses a familial case of DBA in which the cousins have cleft palate. Interestingly one cousin has DBA, requiring treatment. The other cousin and his sister have hematologic manifestations of DBA but have not been anemic or require any treatment. The mothers of the children are completely normal physically and hematologically even though they must be "carriers" of the DBA gene. DBA patients with cleft palate may represent a distinct clinical phenotype of DBA.

  Gripp KW, McDonald-McGinn DM, LaRossa D, McGain D, Federman N, Vlachos A, Glader BE, McKenzie SE, Lipton JM, Zackai EH.

  Am J Med Genet. 2001 Jul 1;101(3):268-74.

  PMID: 11424144

- **Hematopoietic stem cell transplantation for Diamond Blackfan anemia: a report from the Diamond Blackfan Anemia Registry.**

  An analysis of the outcome of hematopoietic stem cell transplantation for DBA was undertaken using the Diamond Blackfan Anemia Registry database. Of the 20 transplanted patients who met criteria for the diagnosis of DBA, 8 underwent an allogeneic HLA-matched sibling hematopoietic stem cell transplant (SCT) and 12 an alternative donor SCT. The survival for HLA-matched sibling versus alternative donor transplant was 87.5% + 11.7% versus 14.1% + 12.1% at greater than 5 years from SCT. This article reviews these outcomes in detail and discusses the risks and benefits of transplantation for DBA.

  Vlachos A, Federman N, Reyes-Haley C, Abramson J, Lipton JM.

  Bone Marrow Transplant. 2001 Feb;27(4):381-6.

  PMID: 11313667

- **Successful immunization following cord blood transplantation in a child with Diamond-Blackfan anemia.**

  Azuma E, Hirayama M, Bonno M, Iwamoto S, Kumamoto T, Kobayashi M, Komada Y, Taniguchi K, Nakano T, Kamiya H.

  Pediatr Hematol Oncol. 2001 Apr-May;18(3):193-7.

  PMID: 11293287

- **Ribosomal proteins S3a, S13, S16, and S24 are not mutated in patients with Diamond-Blackfan anemia.**

  Cmejla R. Blafkova J, Stopka T, Jelinek J, Petrtylova K, Pospisilova D.

  Blood. 2001 Jan 15;97(2):579-80. No abstract available.

  PMID: 11202430

• Evidence for linkage of familial Diamond-Blackfan anemia to chromosome 8p23.3-p22 and for non-19q non-8p disease.

Blood from 12 multiplex DBAR families and others from Europe was analyzed through genetic linkage. Evidence was found that another gene for DBA exists on chromosome 8p. This locus is defined and candidate genes are being investigated.

Gazda H, Lipton JM, Willig TN, Ball S, Niemeyer CM, Tchernia G, Mohandas N, Daly MJ, Ploszynska A, Orfali KA, Vlachos A, Glader BE, Rokicka-Milewska R, Ohara A, Baker D, Pospisilova D, Webber A, Viskochil DH, Nathan DG, Beggs AH, Sieff CA.

Blood. 2001 Apr 1;97(7):2145-50.

PMID: 11264183

• Osteogenic sarcoma associated with Diamond-Blackfan anemia: a report from the Diamond-Blackfan Anemia Registry.

This article discusses the association of DBA with osteogenic sarcoma, a rare bone tumor that has been found in patients from the DBAR. Other cancers seen in DBA patients and their relatives are also reviewed.

Lipton JM, Federman N, Khabbaze Y, Schwartz CL, Hilliard LM, Clark JI, Vlachos A.

J Pediatr Hematol Oncol. 2001 Jan;23(1):39-44.

PMID: 11196268

Thank You for Your Support During 2001

Thanks to the commitment and hard work of the families and friends of the Diamond Blackfan Anemia Foundation, Inc. (DBAF). Contributions for the year 2001 totaled over $325,000.00. These contributions were achieved through various fund raising events; donations made either in honor or in memory of loved ones (Honor and Memorial Cards are available through the DBAF upon request), directed donations through the United Way and workplaces, and personal gifts.

We are grateful to the families and friends of the following DBA patients for providing the DBAF the opportunity to continue funding worthwhile research projects. A sampling of the fundraising events held in honor of DBA patients are: letter writing campaigns, chicken barbeques, golf tournaments, duck race, bake sales, garage/rummage sales, formal dinner dances, silent auctions, concerts, marathons, walkathons, "Dance for DBA", celebrity sporting events, fashion shows, backyard carnivals, book sales, plant sales, raffles, and more. Perhaps the most touching of all are the donations made by the children themselves. A dollar bill tucked carefully inside an envelope requesting "it be given to a smart doctor to find a cure", a young girl who requested that instead of birthday presents, her guests make a donation to the DBAF to help her sister, a young boy who donated his holiday bonus from his paper route because "he really, really loves his brother". Whatever the donation, whatever the means, we appreciate the support and encourage all families to do their part in continuing our mission.

Philip Ash
Justin Baumgardner
Lindsey Baur
James Bohuski
Alexandra Braue
Paula & Sarah Browning
Sean Cadden
Fisher Coan
Gail Coughlin
William Fair
Arash Fathizadeh
Gabriella Ferrari
William Fair
Kevin Gately
Shayna Goldrich
Kathleen Grace Green
Erik Harrison
Alexandria Hartmann
Natalie Hianek
Michael Joyce
Mark Larkin
Jason Lingham
Harry Major
Paige Mauch
Andrew & Michael McCaughey
Nancy McSweeney
John-Paul Quintero
Kyle Rashford
Michael Sinatra
Carson Souza
Ryan Spring
Christopher & Matthew Vroman
Andreas Wagner
Dan Wagner
Atleigh Whitman
Jessi Williams
Paul Witzgall

In memory of Katie James

DBAF News

Update on Sandra Cruz's Condition

Sandra's mom is a former member of the Board of Directors of the DBAF

Sandra received her sister's bone marrow on November 29, 2001. Sandra is truly a strong little girl full of hope and determination. She was hospitalized for only 48 days, which according to her doctor, was the shortest stay he has ever witnessed. During the aggressive chemo treatment, Sandra predicted her release date to be December 30, 2001. Of course, her doctor did not think her prediction would be possible, but as predicted, Sandra was more than ready to go home by December 28th.

I thank God that Sandra's transplant went smoothly, and with very few complications. She suffered mentally and physically to the point that one day she asked me if she was going to die. I believe what helped Sandra the most was her attitude and her thirst for life, a life without DBA. Her determination is so strong that I now truly believe she will be O.K.

The lesson learned from this ordeal is to have faith in God and oneself which is something I have learned from little Sandra. She was the strong one. She was the one that made plans for the future, a future without DBA, and without blood transfusions and chelation every other day. Sandra saw the light in the midst of her pain and refused to let the physical pain overpower her life. I came into this with a lot of worry and fear of the unknown and with little faith in God. But Sandra has taught me otherwise.

Sandra continues with her progress. She has not received blood transfusions since early December and the beauty is that her hemoglobin has been steadily maintained between 9.0 and 11.0. Originally, her doctor did not want her to attend school until next fall but he is reconsidering and may allow her to attend summer school.

I keep asking her doctor if she is DBA free. His response is always vague saying it will take one year to really find out. But I know in my heart that she is cured.

I want to take this opportunity to thank the many people who prayed for us during these hard times. I thank you from the bottom of my heart. This experience has shown me that there are many humane people out there and many people who care deeply. A special thank you to our friends for keeping in touch with us. And last but not least, thank you little Sandra for wanting to live life and to Monique for giving her life.

Southern California Family and Friends - Fundraiser for DBA

On October 20, 2001, in just a three-week time period, friends and family of Marissa Ybarra put together a fundraiser at beautiful Santa Anita Park in Arcadia California. We had a full day of fun and excitement for all ages with Pony Rides, Face Painting, and four moon bounces along with a picnic style lunch. We raised $1,367.00 for DBA.

Marissa, along with her twin brother Sal Ybarra, met a new friend, 18 year-old Danielle Hernandez, who also has DBA. Danielle and her family read about the fundraiser in our local newspaper. How wonderful it was that this event not only raised funds but also brought Marissa a new friend with whom she bonded with immediately!

Hopefully we have reached many families through several news articles. We graciously thank all those who supported our first fundraiser and we look forward to having another soon. We also want to thank Dr. Thomas C. Hofstra who has effortlessly cared for Marissa since her birth at the Children's Hospital in Los Angeles. Marissa currently takes 4 mg's of Medrol every other day (2x2x1) and rinses her mouth with Bactrin on weekends. She also has osteoporosis in both her knees for which she sees an endocrinologist at Children's Hospital. She has responded well to Medrol and in just the last few months her hemoglobin is now at 11.5.

Our family also sends our love and prayers to Sandra Cruz who lives near Marissa and her family. We send a heartfelt thank you to the Baumgardner Family as well who assisted us in the procedures, policies, and ideas for this successful fundraiser!

NIH Recruiting Patients for Stem Cell Mobilization Trial

The Hematology Branch of the National Institutes of Health is currently recruiting patients for its study "Investigation of G-CSF-induced stem cell mobilization in patients with Diamond-Blackfan Anemia". This study was designed with the hope that gene therapy will one day be an effective treatment for Diamond-Blackfan Anemia. It examines whether people with DBA have a normal response to a process called "G-CSF-induced stem cell mobilization". This process, combined with a procedure called "leukapheresis", is the standard method used to collect the "stem cells" that give rise to all the blood cells in the body. Collection of these "stem cells" is necessary for successful gene therapy.

In order to be eligible for the trial, those with DBA must be at least 4 years of age, weigh at least 27 pounds, and be red-cell transfusion dependent.

Detailed information on this trial can be obtained at the NIH website "ClinicalTrials.gov" under protocol number 01-H-0097, or by contacting the NIH Patient Recruitment and Public Liaison Office at telephone number: 1-800-411-1222 or e-mail: prpl@mail.cc.nih.gov.

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dbafoundation.org

DBA Foundation Website

The DBA Foundation, Inc. is pleased to announce the unveiling of the Foundation's website. This site was designed with many users in mind. There is a special section for patients and families of patients with DBA. There is one section for medical professionals and one for researchers. We hope that you will find this site useful in keeping you informed on the issues and advancements that effect people with Diamond-Blackfan Anemia.

Please visit the new site at www.dbafoundation.org.

If you would like to contribute a story, information, or a picture to be included on the website, please contact the foundation at: info@dbafoundation.org.

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Have You Registered With DBAR?

The Diamond Blackfan Anemia Registry (also known as the DBAR) was established in 1993 as a database for all DBA patients and families in the Unites States and Canada. There are 361 patients registered in the DBAR. Unfortunately complete questionnaires have been received on only 120 patients. Many families have completed the information, however the questionnaires have not reached our office. With the help of the DBA Foundation, a part-time Research Associate has been hired. Eva Atsidaftos is able to help you complete the questionnaire and answer any related DBA questions. Please contact us at the toll-free number listed below to inquire about your information. Updates in your or your child's medical condition are greatly appreciated.

To all new families, please contact Eva or myself to join the DBAR. In such a rare disease, information on every patient is extremely valuable. Please help in the research effort and share your data. All information will be kept confidential.

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