

\_\_\_\_(DATE)\_\_\_\_

*(for Congressmen/women)*

Honorable \_\_\_\_ (first/last name of Member)\_\_\_\_  
United States House of Representatives  
\_\_\_\_(add building name)\_\_\_\_ House Office Building  
Washington, DC 20515

**-OR-**

*(for Senators)*

Honorable \_\_\_\_ (first/last name of Senator)\_\_\_\_  
United States Senate  
\_\_\_\_(add building name)\_\_\_\_ Senate Office Building  
Washington, DC 20510

Dear Representative \_\_\_\_ (fill in last name)\_\_\_\_:

**-or-**

Dear Senator \_\_\_\_ (fill in last name)\_\_\_\_:

I am writing with regard to Diamond Blackfan Anemia (DBA) and Pediatric Acquired Brain Injury (PABI).

DBA is a rare genetic bone marrow failure disorder characterized by severe anemia. This anemia is caused by an inability to make red blood cells which carry oxygen to all tissues in the body. DBA is unique – as the first human disease linked to a ribosomal protein deficiency – and research into DBA has broad implications: yielding valuable insights into blood disorders, blood cell formation, cancer, the genetics of birth defects, and more. The great potential and wide-ranging applications of further DBA research justify sustained support of Members of Congress such as you.

As you may know, PABI is the NUMBER ONE cause of death and disability for children and young adults in the United States; yet despite that fact, very few average Americans recognize PABI as a significant problem, which only serves to exacerbate the problem within the medical and educational communities. To compare numbers with a commonly recognized condition (autism), the CDC currently estimates there are over 1.4 million NEW brain injuries that occur EVERY year, but there have been only 560,000 TOTAL number of children up to age 21 who have been diagnosed as being on the autism disorder spectrum. PABI is an under-recognized, under-funded, misunderstood national health epidemic!

*[If you have a personal anecdote relating to your experience as a DBA or PABI family, or your general support of DBA and PABI and DBA & PABI research, please include your story here].*

As you may know, House Resolution 524, expressing the sense of Congress regarding Diamond Blackfan Anemia (DBA), was passed by the House of Representatives in the 110th

Congress. The resolution, introduced by Representative Carolyn McCarthy and co-sponsored by 107 Members of Congress, is an important resolution recognizing the significant scientific and clinical achievements brought about by DBA research and acknowledges the foresight of the National Institutes of Health and Centers for Disease Control in their active involvement in DBA initiatives.

Additionally, I ask that you support the National Pediatric Acquired Brain Injury Plan (PABI Plan) Grant Proposal. Please see the website at [thebrainproject.org](http://thebrainproject.org) for more information about this plan.

*[If the official you are writing to is one of the 107 original co-sponsors, include:*

“I would like to thank you for your co-sponsorship of this resolution.”] It is very important to me and my family that you understand the importance of supporting rare disease research, and DBA research in particular, and that you will continue to support the exciting DBA initiatives at the NIH and CDC. It is just as important to us that you support the initiative to fund the PABI-Plan.

Sincerely,