**Diamond Blackfan Anemia Registry (DBAR)**

**Yearly Update Form**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Patient’s Last Name | | | | First Name | | | Middle Initial |
| Date of Birth | DBAR # | Sex | | Email Address | | | |
| Primary Phone (Home) | | | Secondary Phone (Work) | | Cell Phone | | |
| Address | | | | | | | |
| City | | | | State | | Zip Code | |
| Name of Primary Physician | | | | Address of Primary Physician | | | |
| Phone Number/ Fax of Physician | | | |
| Name of Hematologist | | | | Address of Hematologist | | | |
| Phone Number/ Fax of Hematologist  **Check all that apply. Please use additional paper if necessary.** | | | |

|  |  |  |
| --- | --- | --- |
| **Genetics**  *O RPL31*  *O RPL5*  *O RPL11*  *O RPL19*  *O RPL26*  *O RPL35a*  *O RPL17*  *O RPL18*  *O RPL27*  *O RPL35*  *O GATA1*  *O TSR2*  O *RPS7*  *O Unknown*  Lab: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  O *RPS10*  O *RPS17*  *O RPS19*  *O RPS24*  *O RPS26*  *O RPS15A*  *O RPS29*  *O RPS28*  *O RPS27*  O *RPS20*  *O RPL15* | **Current Treatment**  O None  O Steroid Therapy  O Red Blood Cell Transfusions  O Chelation Therapy  O Desferal®  O Exjade®  O Jadenu®  Dose: \_\_\_\_\_\_\_\_\_\_  O Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_ | **Current Status (Include dates)**  O Steroid dependent  Current Dose:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  O Chronic transfusion dependent  Current Schedule:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  O Remission  O Stem cell transplant  O Aplastic anemia  O Leukemia  O Myelodysplastic syndrome |
| **Other Relatives with DBA**  O None  O Sibling  O Parent  O Grandparent  O Aunt/Uncle  O Cousin  O Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  O Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | **Remission**  O Never  O In past  O At present  O Duration \_\_\_\_\_\_\_\_\_\_\_\_ | **Current Medications (Include Dose)**  O Prevacid  O Zantac  O Blood Pressure pill  O Insulin  O Growth Hormone  O Birth Control medication  O Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  O Other \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

**Other Health Issues**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**