

# Children's Hospital Boston's Hematology Clinical Research Program

Children's Hospital  
300 Longwood Avenue  
Boston, MA 02115



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## **Pediatric MDS and BMF Patient Registry and Tissue Bank**

### **What is the registry and tissue bank?**

The Hematology Department is creating this patient registry and tissue bank to collect data on pediatric myelodysplastic syndrome (MDS) and patients with acquired or inherited bone marrow failure (BMF) disorders, a related group of diseases about which very little is known. Through systematical and in depth analysis of the data, we aim to create a comprehensive database that will allow us to better classify and understand pediatric MDS and BMF. Long-term we hope to store well annotated pediatric MDS and BMF tissue samples for future analysis so we can define the genetics of childhood MDS, how the disease relates to BMF disorders, identify pathways for therapy, and ultimately translate this knowledge to improved outcomes.

### **Who can participate?**

Anyone under the age of 35 who has a confirmed or suspected diagnosis of primary MDS or one of the following conditions:

- Suspected or known diagnosis of primary MDS (including familial MDS)
- Suspected or known diagnosis of secondary MDS
  - Secondary to bone marrow failure disorders
  - Secondary to chemo- or radiation therapy
- Suspected or known diagnosis of Myeloproliferative Disorders such as
  - Myelofibrosis (MF)
  - Essential Thrombocythemia (ET)
  - Polycythemia Vera (PV)
- Suspected or known diagnosis of Myelodysplastic (MDS)/Myeloproliferative Disorder (MPD)
- Suspected or known inherited bone marrow failure disorders such as
  - Fanconi Anemia (FA)
  - Dyskeratosis congenital (DC)
  - Severe Congenital Neutropenia (SCN)
  - Schwachman-Diamond Syndrome
  - Diamond-Blackfan Anemia
  - Bone marrow failure, NOS
- Acquired Severe Aplastic Anemia and Very Severe Aplastic Anemia

### **What will happen if I decide to participate?**

If you are eligible and want to participate, you will begin with a diagnostic evaluation, including diagnostic procedures including blood, bone marrow and germ line tissue samples. We will also collect your demographics and a complete medical history. In regular time intervals (6-12

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months), we will request follow up samples. Your follow up period will last a minimum of one year and a maximum of 10.

## **Who should I contact if I want more information?**

If you want to learn more about this study, please call either of the following people:

Dr. Inga Hofmann, Principal Investigator	617-632-2463
Dr. David Williams, Co-Investigator	617-919-2697
Jennifer Braunstein, PNP, Research Nurse	617-355-2457

You may also email us at [mds@childrens.harvard.edu](mailto:mds@childrens.harvard.edu)