

SDS Registry Background and Joining Process as of July 2012

The SDS Registry was finalized in 2008 after many years of organizing it, creating the framework for it, creating the software program for it and finding funding. The initial cost for this was approximately \$100,000 which was mostly funded by SDS Project, an organization that focuses on funding the registry and cord blood research projects.

The goals of the registry are to: collect clinical information from SDS patients to create a database of information that can be organized and culled for very specific types of information. This information can be accessed by approved scientists for research that could improve diagnosis, medical management, treatments and perhaps lead them towards a cure! Specimens of blood, tissue and bone marrow are also collected to aid in this endeavor.

We need as many SDS patients to enroll in this registry as possible. The more patient data is collected, the more research can be performed on the data and the more information can be learned about issues like: can early markers be identified for aplastic anemia? Leukemia? or can novel treatments be created to stop bone marrow failure and so many other issues.

To start the process of joining the Registry, contact the registry via email/phone and they can walk you through all of the consent and HIPPA forms that you can download on their web site. This is an important step that is required by the Fred Hutchinson Cancer Care Center in order to be compliant with their regulations of having a registry at their facility. The Registry **CAN NOT CONTACT YOU FIRST.** You must call/email them first. This gives them permission to contact you back at any time.

Send Your patient Records Annually. We all must try to remember to gather the patient's medical data and/or give written permission to all of their doctors to **ANNUALLY** send to the Registry. Hopefully, the Registry will contact you to remind you but it is good for us to remember too.

We then have to remember to **contact the registry prior to going to any bone marrow biopsy or CBC** collection as the SDSR study staff will help the patient and/or family coordinate obtainment and shipment of the samples. Samples must be shipped Monday through Wednesday except in the case of an emergency procedure. Please contact the Registry regarding sending samples 2 weeks to 1 month prior to your sample collection.

The bottom line is that checking in regularly with the Registry can help us remember to include them in our planning for medical record keeping and tissue collection.

www.sdsregistry.org

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