

The National MDS Natural History Study



We are very fortunate that the National Heart, Lung and Blood Institute at NIH has allotted funds for the National MDS Natural History Study. This is a remarkable opportunity for all of us.

For years, we have tried to draw conclusions about what MDS is like from the first time it's even suspected all the way through a person's disease course. We have no idea about this because we have never looked at it from that first point in time and followed them for years afterwards. The National MDS Natural History Study is looking at patients who have a suspected diagnosis of MDS who will be getting a bone marrow biopsy, or those who have a recent MDS diagnosis who are about to undergo another bone marrow biopsy.

We want to approach people at that stage, and ask if they would be willing to answer some questions about other illnesses they have had, what some of their long-term environmental exposures have been, what medications they are on or have been on, and any past history of cancers. We will also ask permission to take a sample of their bone marrow and blood so we can study it over time.

This is a seven-year study, and we plan to enroll 2000 MDS patients across the country and another 500 patients who have blood abnormalities but who do yet not have a formal MDS diagnosis. In addition, we are going to enroll another 1000 patients who don't fall into one of those two categories, so in the future we can conduct the exciting research that we need to be doing in real time.

This study also allows us to try to determine what some of the causes of MDS are. We have always speculated about what environmental exposures could have led to MDS. It could be common like smoking, or uncommon like prior radiation therapy.

We have also discovered MDS in patients after they have been treated with radiation or chemotherapy for other cancers. Whether those people truly have MDS as a result of the treatment or if the MDS came up spontaneously and had nothing to do with prior exposure to radiation or chemotherapy is something we currently have no insight into. With this study, we will be able to answer questions like this.

Mikkael Sekeres, MD, MS



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Vice Chair for Clinical Research at the Cleveland Clinic Taussig Cancer Institute. Dr. Sekeres completed his postgraduate training at Harvard University, finishing an internal medicine residency at Massachusetts General Hospital and a fellowship in hematology-oncology at the Dana-Farber Cancer Institute in Boston.

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The nice thing about this study is that there's very little people have to do above and beyond what they would ordinarily be doing for medical care in their situation.

The most important requirement is that someone has had a bone marrow biopsy or is about to have one. This is because we will be asking that person to provide us with additional samples from the bone marrow for a lot of the critical studies we will be doing over time to understand the biology of MDS.

Potentially interested participants need to know that questions will be asked. At the very start, we will ask them to provide information on their background, exposures, and their illness, and as time passes, fill out quality-of-life forms.

Any center that would normally participate in a national cooperative group study within the NCI mechanism can participate in this nationwide study. There's the potential for 2000 centers to participate. Although we can't expect all of them to join, we do hope at least several hundred will. We currently have about 200 centers involved.

If you are an MDS patient, my advice is to ask your doctor or health care provider if there's an opportunity for you to participate. If you are a physician, consider opening this study and enrolling your eligible patients in it. It will help answer absolutely critical questions about the natural history of MDS. ■

For more information about the National MDS Natural History Study

Visit www.thenationalmdsstudy.net or call the National Cancer Institute's Cancer Information Service (1-800-4Cancer/1-800-422-6237).

The National MDS Natural History Study is sponsored by the NIH National Heart, Blood and Lung Institute, in collaboration with the National Cancer Institute.

Supporting Our MarrowStrong Community

AAMDSIF remains the sole global nonprofit organization that provides the resources patients and their family members need to understand what happens in the wake of a bone marrow failure diagnosis.



As you know, we receive some funding from pharmaceutical companies but rely heavily on generous contributions from individuals.

I ask that you give often and as generously as you can so that we can continue to be an important resource for everyone in our community.

Consider monthly giving – it allows us to be more efficient and it is easy for you as well.

www.aamds.org/donatenow

Thank you,

Kevin Lyons-Tarr, Chairman of the Board

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PATIENT STORY

Jane Massey's Route to Diagnosis



Although it sounds strange, I am beginning to believe that breast cancer has possibly saved my life. In October 2015, I was diagnosed with stage 2 lobular carcinoma of the breast. My cancer was found during my routine mammogram.

I opted for a bi-lateral mastectomy and then had 33 radiation treatments in early 2016. I saw my oncologist every month due to my treatment and she ran blood work every time. My numbers had been a little off for some time prior but nothing too worrisome.

However, my oncologist began to notice that my numbers were not improving- actually there was a continual decrease in my hemoglobin, hematocrit, and my red and white blood cell count. She ran several tests, and I had a liver biopsy. After a while she decided that a bone marrow biopsy was needed. When we returned for the biopsy results, we were shocked at my doctor's words.

My oncologist said I had MDS, specifically the 5q deletion subtype. She explained that this typically is only seen in people around age 70. She said that the best treatment for a 50 year-old like me, would likely be a bone marrow transplant. She then referred me to Kansas University (KU) Cancer Center in Kansas City, because they were the closest transplant center to our home.

We went to KU the next week and began meeting with the staff there, and they explained the process to us. He agreed that transplant was my best option. KU performed another bone marrow biopsy. After the doctors consulted with each other it was determined that my blast count (young, immature white blood cells) was better than expected so we could hold off on an immediate transplant. They decided to put me on an oral medication, lenalidomide (Revlimid®) and see if that helped my blood counts. Thus far it has worked as hoped, so I will be on my current regimen for the foreseeable future.

In the meantime, KU had my brother and sister tested to see if they were a donor match for me. It was found that they were a 100% match to each other. We had to wait for insurance approval to test my tissue with theirs.

My daughter, Sara, decided she couldn't wait to see if they were a donor match and started the process with DKMS to see about a donor drive! The thought of people coming and getting swabbed to see if they could help me was overwhelming and humbling. My family and church family were awesome with their support of encouragement and prayer.

My insurance finally gave approval to test my tissue and we couldn't believe the results. Not only did I match my brother but I matched my sister 100%! We had been told that there was only a 25% chance for a 100% match to a sibling.

Sara decided to continue with the drive because there are so many patients who are not as fortunate as me. I have a couple of friends that may end up eventually needing a transplant because of their blood diseases, and maybe this will help them. I want to do what I can to help others. So I will learn more about blood disease and be an advocate for those needing a transplant. ■

SHARE YOUR STORY!



We are looking for MDS patients, family members and caregivers who are interested in sharing their personal stories with our community.

They can be funny or poignant, a chronology of key events or a single anecdote that sums up the ways in which your world has changed because you live with a chronic disease.

There's no right or wrong way to talk about how MDS has affected your life. You might reflect on the impact on your family or the ways you are coping with treatments, transfusions and fatigue. Are you participating in a clinical trial? Have you developed new skills to help you stay positive? Whatever story you choose to tell, we'd love to read it.

Please consider sharing your health journey with us in a 500-700 word article. If you're not sure where to start, you can find lots of patient stories at:

www.aamds.org/support/stories-of-hope.

Email editor@aamds.org to submit your story, and remember to include your photo in .jpg format. Be sure to include the date of diagnosis, age at diagnosis, age today, name, address, daytime phone and email address.



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Connecting is Strength**

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