



The National Myelodysplastic Syndromes (MDS) Study

Recruiting patients with low blood counts undergoing a bone marrow assessment for evaluation of MDS



Does your physician suspect you have a blood condition that requires you to have a bone marrow biopsy for diagnosis? If so, you may be able to participate in the NHLBI-MDS research study.

The National Institutes of Health (NIH) is conducting a research study called the **National Myelodysplastic Syndrome (MDS) Study** (also known as **NHLBI-MDS**). NHLBI-MDS is an observational study, which means that you will not be treated as part of the study. Instead, your health will be closely followed during routine medical visits.

Because MDS is a rare blood disorder, scientists and doctors want to learn more about it. The purpose of NHLBI-MDS is to gather information about MDS that will be used to learn as much as possible about the disorder. The information collected will enable scientists to conduct research on how to improve the way MDS is diagnosed and treated. Most importantly, the NHLBI-MDS study will help patients and their families better understand what to expect when diagnosed with MDS.

Racial and ethnic minorities are encouraged to talk with their doctor about participating in this study. This will help researchers to better understand how MDS affects these populations.



You may be able to participate in NHLBI-MDS if:

- You are 18 years of age or older.
- Your doctor thinks that you have MDS, or you are seeking a second opinion for a previous diagnosis of MDS, **AND** you're told that a bone marrow biopsy is needed.
- You have not been recently diagnosed with cancer.

Once you agree to be in the study:

- You will have a clinical examination and a bone marrow biopsy.
 - During the bone marrow biopsy, additional samples will be collected for research use.
- You may be assigned to the long term follow-up group, which means you will have a follow-up visit every 6 months (when you are already scheduled to meet with your doctor).

In your follow-up visits:

- The doctor or nurse will ask you questions about your medical history and you will be asked to complete a survey to assess your well-being.
- A doctor will examine you and you will have your blood taken.
- At your first exam only, a clinician will collect:
 - A few of your eyebrow hairs using a tweezer, and
 - Cells from inside your cheek using a small cotton swab
- Also, if you have a bone marrow procedure as part of your clinical care, additional samples will be collected for research use.

If you would like to learn more:

- Visit the National MDS Study website: <https://thenationalmdsstudy.net/index>
- Visit www.ecog-acrin.org and search NHLBI-MDS, then select the link to NHLBI-MDS
- Call the NCI Cancer Information Service at 1-800-4-CANCER (1-800-422-6237)