

The National Myelodysplastic Syndromes
Natural History Study
Resource Request Portal

Sponsored by the National Heart, Lung, and Blood Institute in collaboration with the National Cancer Institute



>1,900 Participants Enr<u>olled</u>



>600
Participants Followed for at Least 12 Months



>1,800 participants with Bone Marrow DNA >1,800 participants with Peripheral Blood DNA



>600
Participants with Follow-up
Quality of Life Assessments



>1,600
Partcipants with Targeted
Sequencing Data*

*472 have whole genome sequencing available via dbGaP

Granular level data:

- Participant diagnostic category
- Medical history
- COVID-19 data
- Charlson Comorbidity Index Score
- Cytogenetics
- Bone marrow assessments
- Lab measures

Biological Specimens:

- DNA
- Plasma
- RNA
- Serum
- MNCs

Data as of 1 September 2023; to be updated annually. For more information go to: www.thenationalmdsstudy.org

The National Myelodysplastic Syndromes (MDS) Natural History Study has launched a web-based portal and invites researchers to request access to a rich clinical dataset, digital H&E slides, and genetic sequencing data collected prospectively from a large cohort of MDS patients enrolled across the US. Resources continue to be added to the database and biorepository as new patients join the study and the existing cohort is followed longitudinally. With the new portal, basic, translational, and clinical scientists can request data to pursue cutting-edge research that will contribute to our understanding of MDS and improve diagnostic and treatment options.

An interactive Inventory Browser allows investigators to assess the types of available biological specimens and associated data. Additional information on the study goals and methodology can also be accessed through the portal.

Study Highlights:

- Over 500 confirmed MDS and MDS/MPN participants have been identified with a projected total of roughly 600 by study end.
- Over 900 participants with cytopenias and suspected MDS have been followed for disease evolution.
- The study has enrolled participants from 160 NCIsupported sites, including academic, community, and VA centers.

Visit the Resource Request Portal



https://thenationalmdsstudy.net/mds-study-information





