The National Myelodysplastic Syndromes (MDS) Natural History Study announces the launch of a new, 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.

The Resource Request Portal is available to the public at: https://thenationalmdsstudy.net/mds-study-information. An interactive Inventory Browser allows investigators to assess the types of available data. Biological samples will be accessible in the future. Additional information on the study goals and methodology can be accessed through the portal.

Study Highlights:
- Over 450 confirmed MDS and MDS/MPN participants have been identified with a projected total of 500 by study end.
- Over 800 participants with cytopenias and suspected MDS have been followed for disease evolution.
- The study has enrolled participants from 272 NCI-supported sites, including academic, community, and VA centers.

Visit the Resource Request Portal

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

Data as of 1 September 2022; to be updated annually.
For more information go to: www.thenationalmdsstudy.org