

**Myelodysplastic Syndromes Foundation**  
**36 Front Street**  
**Box 353**  
**Crosswicks, NJ 08515**

**Personal Information Authorization for Research Screening Database**

The Privacy Regulations issued under the Health Insurance Portability and Accountability Act (HIPAA) require researchers to get permission (or waivers) before using or disclosing protected health information (PHI) for research. The Myelodysplastic Syndromes (MDS) Foundation maintains a clinical and research database to store personal health information as part of an international database registry (ADOPT). We are asking your permission to store your personal information in our database as described below. This is completely voluntary and will not affect any treatment or other services to which you would normally be entitled. The database may help to identify new clinical studies (or trials) for which you may be eligible. Any use of this information for a particular research study will not occur until either you sign a new study-specific authorization or the study obtains a waiver of authorization.

**What personal information we keep in our database**

- **Demographic information:** name, address, phone number, date of birth, race and gender.
- **Medical information:** diagnosis, lab results, current treatments, physician's names and numbers.

**Who will have access to your personal information**

The information will be stored in a computer at the office of the MDS Foundation.

**How long we will keep your personal information in our database**

We will keep your information in our electronic database indefinitely. You may ask us to remove your information from our database at any time.

**How your personal information will be used**

Staff members may periodically search our database looking for individuals who have expressed an interest in research and/or are qualified for specific research opportunities based on their personal information. Staff members may then contact you via telephone, mail or email to offer research opportunities. Our staff may ask you questions about your health and record your answers. A record of all contacts with you and your responses will be kept in the electronic database. We may also contact you periodically to share general information about our group or our research opportunities.

**How your personal information will not be used**

We will not release or share your personal information with anybody outside of the MDS Foundation or the University of Rochester Medical Center/Strong Health system for any reason

**AUTHORIZATION**

By signing this form, I authorize the MDS Foundation to store my personal information in an electronic database. I understand that I can revoke this authorization at any time by written request to the MDS Foundation at the address on the top of this form.

Are you currently interested in participating in research?     **Yes**     **No**

Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_  
*Adults or children able to give permission.*

Name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_  
*Surrogate/ Guardian/ Health Care Agent/ Parent or Legal Guardian of those not able to give permission. (Circle one)*

*Note: Provide one copy of this form to the individual signing the authorization.*