MDS Registry Underway

In the summer of 2006, Boston University’s Slone Epidemiology Center began its myelodysplastic syndromes (MDS) patient registry. Known as the Patient Registries at Slone: MDS, this national registry enrolls patients who have recently been diagnosed with MDS. Participants complete questionnaires at enrollment and every six months thereafter. Boston University researchers are analyzing information collected from these questionnaires.

MDS Registry Participants

![Graph showing age distribution of MDS participants]

and from participants’ medical records to help doctors and other health care providers better understand the effects of MDS and its treatments on patients’ well-being. To date, over 150 patients are participating. Approximately half are men and half are women. Their average age is 65 years. As the chart above shows, patients range in age from young adults to those well into their 80s.

Registry staff are busy contacting participants who have not yet had the opportunity to complete their questionnaires by mail or on the internet. Trained interviewers are happy to spend time taking the questionnaire information by telephone. The study director, Dr. David Kaufman, is shown above with two staff members, Melissa Quinn (left), Research Data Coordinator, and Barbara Winters, RN, Nurse Interviewer and Medical Record Abstractor. David, Melissa, Barbara, and all our staff would be happy to answer your questions about the registry and look forward to talking with you.

We thank you for your interest in the Registry and for your continued participation.

A Word from... Dr. Richard Stone

Clinical Director of the Adult Leukemia Program at the Dana-Farber Cancer Institute in Boston and clinical advisor to the PRS: MDS.

“Participants in the MDS patient registry are helping doctors and researchers better understand the ‘real world’ experiences of MDS patients. We genuinely appreciate your time and effort in answering our questionnaires and are eager to begin analyzing the valuable information that you provide.”
Do you have questions about the Registry?
Has your name, address, or telephone number changed?
Please contact us.

**POSTAL MAIL:**
PRS: MDS
Slone Epidemiology Center at Boston University
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Boston, MA 02215

**FAX:**
617-738-5119

**EMAIL:**
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**WEBSITE:**
www.bu.edu/prs/mds

Please feel free to share this newsletter with others who may be interested in learning more about this project. You will find copies on our website at:

www.bu.edu/prs/mds/mds-newsletter

*The Registry has been approved by the Boston University Institutional Review Board and is conducted with the guidance of an independent Advisory Board.*