

**THERE ARE 2 WAYS TO COMPLETE THIS SURVEY
(IT SHOULD TAKE NO MORE THAN 10 MINUTES OF YOUR TIME):**

1. Simply complete this form and return it to the MDS Foundation via mail or fax.
2. Complete the survey online by logging on to our website at www.mds-foundation.org.

Myelodysplastic Syndromes Practice and Treatment Survey

Sponsored by the MDS Foundation, Inc.

Overview and Objectives: The MDS Foundation recognizes that data on many aspects of MDS worldwide is sketchy or nonexistent. While individual investigators have developed databases to track MDS within their individual sites or working groups, that information is not located within one easily accessible database.

The Foundation has attempted to design a survey that we hope will assist in describing some of the issues related to MDS worldwide as well as the treatments being utilized in this disease. While we know that this information is, in most instances, based on subjective criteria it can assist in identifying educational and research opportunities in the near term and until more accurate data is available.

The results of this expanded survey will be shared with each of our Centers of Excellence and used by the Foundation to assess new educational and research opportunities. Thank you in advance for your consideration in completing this form.

1. Please indicate country in which you practice: _____

Is your practice based at: An academic hospital A community-based hospital Private practice

2. How many MDS patients do you treat in your practice or institution each year?

None 1 to 10 11 to 25 26 to 50 51 to 100 More than 100

3. In the past five years did the number of patients you see for MDS increase, decrease, or remain the same? (Please check one.)

Increased Decreased Remained the same

4. If the number of patients you see has increased please tell us why you feel this increase has occurred?

(Please specify by typing or writing your response below.)

5. How often do you see each of your MDS patients? Monthly Every 3-6 months Annually

Only with clinical indication of disease progression Never, they are referred

6. Do you tell your patients that MDS is a cancer? Yes No

Why or why not? (Please specify by typing or writing your response below.)

7. When patients are referred to you how are they classified by the referring physician? *(Please check all that apply.)*

Not categorized International Prognostic Scoring System (IPSS) French-American-British (FAB)
 World Health Organization (WHO) Other *(If other, please specify by typing or writing your response below.)*

8. How are patients classified in your practice or institution? (Please check all that apply.)

- Not categorized IPSS FAB WHO
 Other (If other, please specify by typing or writing your response below.)

9. If you do assign an IPSS or WPSS score, who at your institution assigns the cytogenetic score?

- Cytogeneticist Hematologist Other

10. Do you monitor your MDS patients with regular bone marrow standard cytogenetics?

- Yes No Only with clinical indication of disease progression

11. If your order cytogenetics and diagnostic BM cytogenetics produces no analyzable metaphase spreads, do you

- Repeat the test immediately Repeat the test at the next scheduled BM Order FISH for del(5q) only
 Order FISH for all or some of the common chromosome aberrations observed in MDS, namely, del(5q), del(7q), +8, MLL(11q23), del(20q)
 Do nothing Not applicable, I do not usually order cytogenetics

12. How often do you request BM standard cytogenetics for MDS patients?

- Only at disease presentation only to confirm/rule out a suspected MDS Every 3 months Every 6 months
 Annually Only with clinical indication of disease progression Never

13. How often does the cytogenetics result impact on your management of patients with MDS?

- Always Sometimes Seldom Never

14. What would be a clinically reasonable turn-around-time for MDS cytogenetics?

- 3 days 7 days 14 days 21 days

15. What percentages of your MDS patients belong in the following IPSS risk categories?

(Please enter the number before the %. Total should be 100%.)

_____ % Low _____ % Intermediate-1 _____ % Intermediate-2 _____ % High Unknown

16. What percent of patients in each of these categories are transfusion-dependent?

(Please enter the percentage in front of each category.)

_____ % Low _____ % Intermediate-1 _____ % Intermediate-2 _____ % High Unknown

17. Do you monitor ferritin levels in your transfusion-dependent patients?

- Yes No

18. How do you determine when to begin chelation therapy in RBC transfusion-dependent patients?

- Increased ferritin levels: >1,000 >2,000 Other amount
 Number of transfusions: How many on average?
 Other criteria (Please specify by typing or writing your response below.)

19. What percentage of your transfusion-dependent patients are receiving chelation therapy? _____%

20. Has the availability of Deferasirox (Exjade®) increased the number of transfusion-dependent patients you place on chelation therapy?

- Yes No

21. Will you begin chelation therapy earlier? Yes No
22. What percent of the low- to intermediate 1-risk MDS patients you see are being:
____% Provided with supportive care only
____% Watched (with no intervention)
____% Actively treated
23. What percent of the intermediate 2- and high-risk MDS patients you see are being:
____% Provided with supportive care only
____% Watched (with no intervention)
____% Actively treated
24. How important are cytogenetic findings in treatment decisions for your MDS patients?
 Very important Somewhat important Important Not Important
25. If you answered that cytogenetic findings are important, which of the currently identified abnormalities most influence your decisions?
26. What types of supportive care are used in your center? (Please check all that apply.)
 Transfusions only (RBC, platelet) Growth factors (G/GM-CSF)
 Vitamins Antibiotics
 Other (If other, please specify type of supportive care by typing or writing below.)
27. Do you use EPO? Frequently Sometimes Seldom Never (skip to question 31)
28. How do you identify patients who may benefit from therapy with EPO?
29. In which diagnosis do you most often use EPO? RA RARS RAEB CMML
30. How do you decide that a patient is non-responsive to EPO?
 No response after 6 weeks of therapy No response after 12 weeks of therapy
 Patient remains transfusion-dependent Other (If other, please specify by typing or writing your response below.)
31. Do you use ATG? Frequently Sometimes Seldom Never (skip to question 34)
32. In which diagnosis do you most often use ATG? RA RARS RAEB CMML
33. What type of ATG do you use?
 Thymoglobulin® (rabbit ATG) Lymphoglobulin, Atgam® (horse ATG)
 Fresenius ATG Other (If other, please specify by typing or writing your response below.)

34. Based on the information available to you, which of the following drugs do you feel will be most useful in treating MDS in each risk category? (Please place a number on the line next to the treatment, with 1 being the most useful and 8 being not useful at all, and specify risk category.)

	RISK CATEGORY			
	Low	Intermediate 1	Intermediate 2	High
___ Arsenic trioxide (Trisox [®])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Anti-thymocyte globulin (ATG)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Cyclosporin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Danazol	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Deferiprone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Erythropoietin (Procrit [®] , Aranesp [®] , Epogen [®])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Deferasirox (Exjade [®])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Desferoxamine (Desferal [®])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Azacytidine (Vidaza [™])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Lenalidomide (Revlimid [™])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Lonafarnib	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Decitabine (Dacogen [™])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Telintra [™]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Thalidomide (Thalidomid [®])	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Valproic acid	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Zarnestra [™]	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
___ Other (If other, please specify by typing or writing your response below.)				

35. In your opinion, what would be most helpful in increasing the referral of patients with possible or presumed MDS to a hematology practice?

- Education of primary care physicians, specialists in private practice or small hospitals, and medical students
- Patient awareness and education programs More clinical trials
- Improved dissemination of data from clinical trials More therapeutic options
- Other (If other, please specify by typing or writing your response below.)

36. Would you be interested in participating in new clinical studies? Yes No

37. Would you be interested in participating in a registry or additional surveys? Yes No

If you have answered yes to questions 36 or 37, please provide your contact information below:

Name: _____

Address: _____

Phone: _____ Fax: _____

E-mail: _____