Myelodysplastic Syndromes Nursing 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 limited in existence. Individual physical investigators have developed databases to track MDS within their individual sites or working groups, however that information is not located within one easily accessible database.

The MDS Foundation has attempted to design a nursing survey that we hope will assist in describing some of the issues related to MDS worldwide as well as treatments being utilized in this disease. While we recognize that this information is, in most instances, based on subjective criteria it can assist in identifying education and research opportunities in the near future.

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

1. Please indicate the country in which you practice:

2. Is your practice based at:
   □ An academic hospital
   □ A community-based hospital
   □ A private practice

3. Please describe your role in caring for patients with MDS: (Check all that apply)
   □ Primary contact
   □ Medical history
   □ Physical examination
   □ Vital signs
   □ Medication dispensing
   □ Education
   □ Other ________________________________

4. How many MDS patients do you treat/care for in your practice or institution each month?
   □ None, 1 to 10
   □ 11 to 25
   □ 26 to 50
   □ > 50

5. In the past five years did the number of patients you see for MDS increase, decrease, or remain the same? (Check one)
   □ Increased
   □ Decreased
   □ Remained the same

6. If you believe the number of patients you see has increased, please tell us why you feel this increase has occurred?
   (Specify your response below)

7. 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
   □ Clinical conditions dictates frequency of visits

Simply complete this form and return it to the MDS Foundation via mail or fax.
The MDS Foundation, 36 Front Street, P.O. Box 353, Crosswicks, NJ 08515
FAX: 1-609-298-0590
8. Do you educate your patients that MDS is a cancer?  ■ Yes  ■ No

9. If patients are referred to you how are they classified by the referring physician?  (Check all that apply.)
■ Not categorized  ■ International Prognostic Scoring System (IPSS)  ■ French-American-British (FAB)
■ World Health Organization (WHO)  ■ Other (specify)

10. Is the classification of MDS readily available to you as a nurse in the patient chart/record?  ■ Yes  ■ No

11. Do you feel you understand the prognostic significance of the IPSS scoring system?  ■ Yes  ■ No

12. Do your MDS patients have cytogenetics performed with every bone marrow exam?  ■ Yes  ■ No

13. Do you believe that cytogenetic results have an impact on the prognosis and management of patients with MDS?  ■ Yes  ■ No

14. What percentage of your MDS patients belong in the following IPSS risk categories?  (Enter percents, so that the total % number is 100%.)
   _____% Low  _____% Intermediate-1  _____% Intermediate-2  _____% High  _____% Unknown

15. What percent of your MDS patients are transfusion-dependent?

16. Do you monitor ferritin levels in your transfusion-dependent patients?  ■ Yes  ■ No

17. How is the decision made to begin chelation therapy in RBC transfusion-dependent patients?
   ■ Ferritin level >1,000  ■ Ferritin level >2,000  ■ Ferritin level of ______
   ■ Number of RBC transfusions: How many, on average?
   ■ Other criteria (specify)

18. Has the availability of Deferasirox (Exjade®) increased the number of transfusion-dependent patients that are on chelation therapy?  ■ Yes  ■ No

19. What types of supportive care are used in your practice?  (Check all that apply.)
   ■ Transfusions only (RBC, platelet)  ■ Growth factors (Epo, G/GM-CSF)
   ■ Antibiotics  ■ Vitamins
   ■ Other (specify)

20. When using EPO how is the decision made that a patient is non-responsive to EPO?
   ■ No Hgb response after 6 weeks of therapy  ■ No Hgb response after 12 weeks of therapy
   ■ Patient remains transfusion dependent  ■ Other (specify)

21. Does your center use any of the following agents to treat your MDS patients?
   ■ Azacitidine  ■ Decitabine  ■ Lenalidomide  ■ Low dose Ara-c  ■ ATG (antithymocyte globulin)

22. If your center is using the agents in question 21, how comfortable are you, as the nurse, with managing the side effects?  (Place an “X” on the scale of 1 to 10, with 1 being very uncomfortable and 10 being very comfortable)

23. Do you use any tracking methods/tools to monitor your MDS patient?  ■ Yes  ■ No
   If yes, please describe your tool:

24. List MDS education resources you use with your MDS patients/families (booklets, web sites)

25. Does your clinical practice site offer participation in a clinical trial as an option for treatment?  ■ Yes  ■ No

26. Would you be interested in educational programs designed for nurses to increase your understanding of MDS/treatment options?  ■ Yes  ■ No
   If you answered yes, would you prefer a:  ■ Live program  ■ Internet available program
   ■ Written program  ■ CD Rom/DVD based program

If you have answered yes to question 26, please provide your contact information below:

Name:_______________________________________________________________________________________________________________________________________________________

Address: _________________________________________________________________________________________________________________________________________________________

________________________________________________________________________________________________________________________________________________________________

E-mail:_______________________________________________________________________________________________________________________________________________________

Phone:_____________________________________________________________________ Fax:_________________________________________________________________________
8. Do you educate your patients that MDS is a cancer? ☐ Yes ☐ No

9. If patients are referred to you, how are they classified by the referring physician? (Check all that apply.)
☐ Not categorized ☐ International Prognostic Scoring System (IPSS) ☐ French-American-British (FAB)
☐ World Health Organization (WHO) ☐ Other (specify)

10. Is the classification of MDS readily available to you as a nurse in the patient chart/record? ☐ Yes ☐ No

11. Do you feel you understand the prognostic significance of the IPSS scoring system? ☐ Yes ☐ No

12. Do your MDS patients have cytogenetics performed with every bone marrow exam? ☐ Yes ☐ No

13. Do you believe that cytogenetic results have an impact on the prognosis and management of patients with MDS? ☐ Yes ☐ No

14. What percentage of your MDS patients belong in the following IPSS risk categories?
(Enter percents, so that the total % number is 100%.)
☐ % Low ☐ % Intermediate-1 ☐ % Intermediate-2 ☐ % High ☐ Unknown

15. What percent of your MDS patients are transfusion-dependent?

16. Do you monitor ferritin levels in your transfusion-dependent patients? ☐ Yes ☐ No

17. How is the decision made to begin chelation therapy in RBC transfusion-dependent patients?
☐ Ferritin level >1,000 ☐ Ferritin level >2,000 ☐ Ferritin level of ______
☐ Number of RBC transfusions: How many, on average?
☐ Other criteria (specify)

18. Has the availability of Deferasirox (Exjade®) increased the number of transfusion-dependent patients that are on chelation therapy?
☐ Yes ☐ No

19. What types of supportive care are used in your practice? (Check all that apply.)
☐ Transfusions only (RBC, platelets) ☐ Growth factors [epo, G/GM-CSF]
☐ Antibiotics ☐ Vitamins
☐ Other (specify)

20. When using EPO how is the decision made that a patient is non-responsive to EPO?
☐ No Hgb response after 6 weeks of therapy ☐ No Hgb response after 12 weeks of therapy
☐ Patient remains transfusion dependent ☐ Other (specify)

21. Does your center use any of the following agents to treat your MDS patients?
☐ Azacitidine ☐ Decitabine ☐ Lenalidomide ☐ Low dose Ara-c ☐ ATG (antithymocyte globulin)

22. If your center is using the agents in question 21, how comfortable are you, as the nurse, with managing the side effects? (Place an “X” on the scale of 1 to 10, with 1 being very uncomfortable and 10 being very comfortable)

23. Do you use any tracking methods/tools to monitor your MDS patient? ☐ Yes ☐ No
   If yes, please describe your tool:

24. List MDS education resources you use with your MDS patients/families (booklets, web sites)

25. Does your clinical practice site offer participation in a clinical trial as an option for treatment? ☐ Yes ☐ No

26. Would you be interested in educational programs designed for nurses to increase your understanding of MDS/treatment options?
   If you answered yes, would you prefer a: ☐ Live program ☐ Internet available program
   ☐ Written program ☐ CD Rom/DVD based program

   If you have answered yes to question 26, please provide your contact information below:
   Name: _______________________________________________________
   Address: _____________________________________________________
   _____________________________________________________________
   Email: _______________________________________________________
   Phone: __________________________________ Fax: ___________________
Overview and Objectives: The MDS Foundation recognizes that data on many aspects of MDS worldwide is limited in existence. Individual physicians have developed databases to track MDS within their individual sites or working groups, however, that information is not located within one easily accessible database.

The MDS Foundation has attempted to design a nursing survey that we hope will assist in describing some of the issues related to MDS worldwide as well as treatments being utilized in this disease. While we recognize that this information is, in most instances, based on subjective criteria it can assist in identifying education and research opportunities in the near future. The results of this survey will be shared with the nursing advisory board and with each of MDS Centers of Excellence and used by the MDS Foundation to assess new educational and research opportunities. Thank you in advance for your consideration in completing this form.

1. Please indicate the country in which you practice:

2. Is your practice based at:
   - An academic hospital
   - A community-based hospital
   - A private practice

3. Please describe your role in caring for patients with MDS: (Check all that apply)
   - Primary contact
   - Medical history
   - Physical examination
   - Vital signs
   - Medication dispensing
   - Education
   - Other ____________________________

4. How many MDS patients do you treat/care for in your practice or institution each month?
   - None, 1 to 10
   - 11 to 25
   - 26 to 50
   - > 50

5. In the past five years did the number of patients you see for MDS increase, decrease, or remain the same? (Check one.)
   - Increased
   - Decreased
   - Remained the same

6. If you believe the number of patients you see has increased please tell us why you feel this increase has occurred? (Specify your response below.)

7. 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
   - Clinical conditions dictates frequency of visits