MDS-Specific Organizations

- Life Beyond Limits
  www.mds-lifebeyondlimits.org
  Brings together an independent group of MDS experts to raise awareness of ageism in access to care for patients with MDS

- MDS Beacon
  www.mdse beacon.com
  Objective and unbiased news and other information related to MDS; mission is to be a key Internet resource and online community for patients with MDS, their families, and others interested in MDS

- MDS Foundation
  www.mds-foundation.org
  Multidisciplinary, international, nonprofit organization dedicated to the education of professionals, patients, and caregivers; facilitation and support of clinical trials; and development and support of patient advocacy groups

- United Kingdom MDS Patient Support Group
  www.mdspatientsupport.org.uk
  Offers support, information, referral advice, and patient information in the United Kingdom

Organizations That Include MDS Within the Scope of Hematologic Malignancies

- Aplastic Anemia and MDS Foundation
  www.aamds.org
  Nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, MDS, paroxysmal nocturnal hemoglobinuria, and related bone marrow failure disease

- Leukaemia and Lymphoma Research Foundation
  www.leukaemialymphoma-research.org
  Programs for support of all of the different blood cancers for patients and their families

- Leukaemia Care
  www.leukaemiacare.org.uk
  Resources for people affected by Hodgkin, non-Hodgkin, and other lymphomas; myeloma; MDS; aplastic anemia; and myeloproliferative disorders

- Leukemia and Lymphoma Society
  www.lls.org
  Mission is to cure leukemia, lymphoma, Hodgkin disease, and myeloma and improve the quality of life of patients and their families

General Resources

- American Cancer Society
  www.cancer.org

- American Society of Clinical Oncology
  www.asco.org and www.cancer.net

- American Society of Hematology
  www.hematology.org

- CancerCare
  www.cancercare.org

- Medline Plus®

- Merck Manual Home Edition for Patients and Caregivers
  www.merckmanuals.com/home/index.html

- National Anemia Action Council
  www.anemia.org

- National Heart, Lung and Blood Institute
  www.nhlbi.nih.gov

- National Marrow Donor Registry
  www.marrow.org

Financial Assistance Programs

- American Cancer Society
  www.cancer.org

- Anthony Nolan Trust
  www.anthonynolan.org
  Dedicated to bone marrow transplantation and running a database of donors

- CancerCare Co-Payment Assistance Foundation
  www.cancercarecopay.org

- Cancer Financial Assistance Coalition
  www.cancercarecopay.org

- Chronic Disease Fund
  www.cdfund.org

- HealthWell Foundation
  www.healthwellfoundation.org

- Lance Armstrong Foundation
  www.livestrong.org

- Leukemia and Lymphoma Society
  www.lls.org/copay

- MacMillan Cancer Support
  www.macmillan.org.uk/ContactUs.aspx
  General information, assistance, and financial advice

- Patient Advocate Foundation Program Co-Pay Relief Program
  www.copays.org

  www.mds-foundation.org/for-patients-visitors

Clinical Trials and International Drug Approval Information

- European Medicines Agency
  www.ema.europa.eu
  Decentralized agency of the European Union, located in London; responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union

- Health Canada
  www.hc-sc.gc.ca
  Provides a notice of compliance (NOC) for full approval of a new drug or an NOC with conditions in Canada

- National Cancer Institute, National Institutes of Health
  www.clinicaltrials.gov
  Registry and results database of federally and privately supported clinical trials conducted in the United States and around the world

- National Institute of Health and Clinical Excellence
  www.nice.org.uk
  Guidance for cost effectiveness of treatments for England and Wales

- Nordic MDS Group
  www.nmds.org
  Provides Nordic guidelines for MDS management online and patient information in all Nordic languages

- Pharmaceuticals and Medical Devices Agency
  www.pmda.go.jp
  Regulation of drug availability in Japan

- Therapeutic Goods Administration
  www.tga.gov.au
  Division of the Australian government’s Department of Health and Aging; responsible for regulating therapeutic goods including medicines, medical devices, blood, and blood products

- U.S. Food and Drug Administration
  www.fda.gov
  Approval required for commercial availability of therapy in the United States

FIGURE 1. Patient and Caregiver Resource Catalog for Myelodysplastic Syndromes (MDS)
The MDS Foundation offers a patient advocacy and outreach program. Patients or caregivers may contact the patient liaison directly by calling (toll-free) 800-637-0839 or via e-mail to ahasan@mds-foundation.org.

Patient Outreach and Advocacy Program

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