Spring 2004 • Volume 9, Issue 1

THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

From the Guest Editor's Desk

H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center
University of Washington
Seattle, WA

Hematopoietic Cell Transplantation for Myelodysplastic Syndromes (MDS)

Bart Scott, MD[1,2] and H. Joachim Deeg, MD[1,2]
[1]Fred Hutchinson Cancer Research Center;
[2]University of Washington, Seattle, WA

INTRODUCTION

Over the past few years transplant and non-transplant options for patients with a myelodysplastic syndrome (MDS) have expanded considerably. The most appropriate timing and indication for a given treatment strategy remain important questions. We will consider the decision making process and will then focus on hematopoietic cell transplantation (HCT), currently the only therapy that offers the potential of cure. We will restrict our comments to patients with primary (de novo) MDS.

Contents

GENERAL CONSIDERATIONS

In regards to risk assessment, the recent WHO classification has made some modifications to the French-American-British (FAB) classification[1], such as separating out patients with a typical "5q-syndrome", with a particularly good prognosis, and patients with "multi-lineage dysplasia", previously lumped with refractory anemia, who tend to have a shorter life expectancy than patients with anemia only.[2] The International Prognostic Scoring System (IPSS) provides improved prognostic precision.[3] According to the IPSS patients are stratified into four risk groups (low, intermediate-1, intermediate-2, and high) on the basis of numerical scores for marrow blast percentage, number of cytopenias (red blood cells, white blood cells, platelets) and cytogenetic abnormalities. This system has proven valuable for both non-transplant and transplant approaches, and has served as the frame work for recent recommendations for transplantation.[4] On that basis, the following policy has been emerging: Patients who fall into IPSS risk categories low or intermediate-1 (generally patients with less than 10% myeloblasts and without high-risk cytogenetics) should be observed or managed conservatively until there is evidence for disease progression. There will be exceptions. For example, a patient with severe thrombocytopenia or neutropenia (or both), even with a low myeloblast count and without poor risk cytogenetics, may be at considerable risk for infections or hemorrhage, and more aggressive management would be indicated, particularly in younger patients. Patients with intermediate-2 or high-risk features by IPSS, on the other hand, if they are transplant candidates to start with and are interested in pursuing that approach, should be transplanted without delay since this strategy offers the best overall life expectancy.

While transplantation continues to be a high risk procedure, results have improved progressively over the years, outcomes with unrelated volunteer donors are comparable to that with sibling donors (largely due to molecular typing and the ability to select closer matches), and the upper age limit for transplantation has moved to 65 years, and to approximately 70 years with reduced intensity conditioning (RIC) regimens.[5-8] There is some data to suggest that if no allogeneic donor is available,

(continued on page 2)

autologous HCT is an option for some patients who achieve a chemotherapy-induced remission, and from whom sufficient numbers of cells can be harvested.

The role of intensive remission-induction and consolidation chemotherapy in MDS before HCT has remained controversial and needs to be addressed in a controlled study. While it appears that patients who receive induction therapy and achieve a remission before transplant will have an improved outcome, it is not clear how the patients should be selected. Most likely pre-transplant therapy selects patients with "chemo-sensitive" disease who also would be more likely to be cured with transplantation even without pre-transplant chemotherapy.[9]

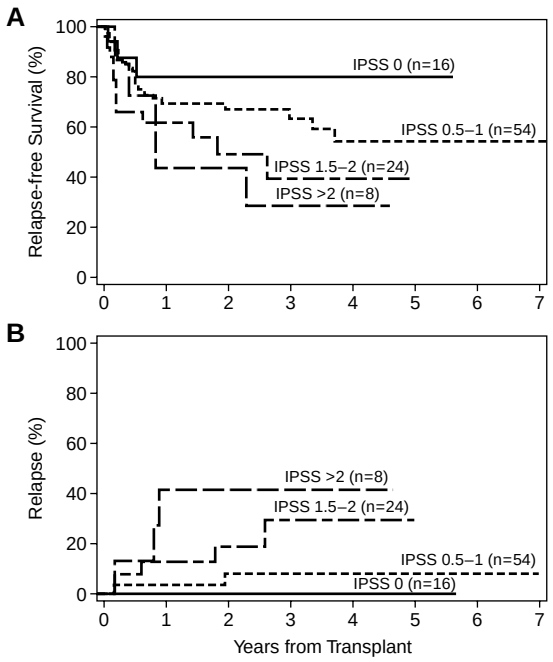
TRANSPLANT APPROACHES

Conventional HCT

The best results with allogeneic HCT are achieved in patients with myeloblast counts of <5% (RA/RARS) at transplantation. Relapse-free survival (RFS) is inversely correlated with the IPSS scores (Figure 1).[10] Age has been a significant risk factor only in some[11] but not in other studies.[10,12] Results with G-CSF mobilized peripheral blood cells tend to be superior to those with cells harvested directly from the marrow (without preceding G-CSF administration). Several studies have suggested that conditioning regimens that do not incorporate *high dose* total body irradiation (TBI) may yield results superior to those obtained with TBI.[10,13]

The European Group for Blood and Marrow Transplantation (EBMT) reported on 131 patients conditioned predominantly TBI-based regimens (70%) and received marrow transplants from HLA-identical siblings. Five-year RFS was 52%, and relapse incidence 13% for RA/RARS patients.[14] In a cohort of 510 patients with MDS transplanted from unrelated donors patients conditioned with busulfan (BU)/cyclophosphamide (CY) fared better than patients prepared with other regimens.[13] RFS and relapse rates in patients with RA were 40% and 5%, respectively.[13] The team at the FHCRC recently reported results with a BU/CY regimen in which the BU dose was adjusted to maintain blood levels of 800-900 ng/mL (targeted BU).[10] Among 69 patients with RA (or RARS) the 3-year probability of RFS was 68% among patients transplanted from HLA-identical siblings, and 70% with unrelated donors.[10] The incidence of NRM among all patients was 12% at 100 days, and 31% at 3 years. Relapse occurred in less than 5% of patients. Another European study compared results with genotypically non-identical family donors or unrelated donors with autologous transplantation.[15] Overall RFS at 3 years was 42% for early stage and 28% for more advanced MDS. Results with transplants from mismatched family donors were comparable to those with unrelated donors, and in fact RFS with autologous stem cell re-infusion was not inferior to either. Nevertheless, the authors concluded that at least for very young patients the better approach may be that of using an alternative donor.

Figure 1. Impact of Pre-Transplant IPSS Score on Relapse and RFS After Allogeneic HCT10



A retrospective survey of the EBMT in 234 patients comparing marrow and G-CSF-mobilized PBPC for allogeneic HCT from HLA-identical siblings (with either TBI- or chemotherapy-based conditioning regimens) confirmed that the incidence of treatment failure was lower when PBPC were used as a stem cell source.[12] In particular, NRM was reduced with PBPC ($P = 0.007$), except for patients with RA or high-risk cytogenetics in whom no difference was observed. The 2-year treatment failure rate was 38% among patients given marrow, and 13% in patients given PBPC.

Thus, these studies show excellent overall results with allogeneic HCT in early MDS with up to 70% RFS and suggest that the lack of a suitably matched related donor should not be cause to abandon plans for transplantation.

The risk of post-transplant relapse increases with the proportion of marrow blasts present at the time of transplantation; relapse rates in the range of 15% to 50% have been reported in patients with RAEB, RAEB-T and sAML[10,13,14] and with increasing IPSS scores (Figure 1).[10,13] A recent report from the International Bone Marrow Transplant Registry on 452 patients transplanted from HLA-identical siblings (44% were conditioned with TBI containing regimens) between 1989 and 1997 showed RFS at 3 years of 40%.[11] The incidence of relapse was 23%, and NRM was 37%. Percentage of marrow blasts before transplantation was the strongest predictor for relapse and RFS, and younger age was correlated with better survival.

Another regimen used a combination of BU and TBI.[16] Results were disappointing, however, and were not improved above those obtained with BU/CY. In an attempt to further reduce NRM, another trial evaluated toxicity and efficacy of a conditioning regimen in which targeted BU was combined with fludarabine (rather than CY).[17] That trial included 38 patients with advanced MDS (or RA with high-risk cytogenetics) transplanted with PBPC from HLA-identical siblings or unrelated donors. The day 100 NRM was 7%, the incidence of acute GVHD II-IV was 54%, and RFS at two years was about 34%.

Other investigators have added anti-T cell antibodies, Thymoglobulin, with encouraging results.[18] In our own experience the use of Thymoglobulin in combination with targeted BUCY is able to reduce the incidence of acute GvHD, thereby reducing toxicity and improving survival (Deeg et al., unpublished).

Reduced Intensity Conditioning (RIC) Regimens

The recent development and application of RIC (or non-myeloablative) transplant regimens ("mini-transplants") has stirred considerable interest.[5-8] The rationale of this approach is that reduction in the intensity of the conditioning regimen will reduce NRM. Post-transplant administration of immunosuppressive drugs (e.g. cyclosporine plus mycophenolate mofetil) will facilitate donor cell engraftment and enhance an effect of donor lymphocytes against the patients' cells. In view of the generally high incidence of NRM in older patients, such an approach is attractive for the treatment of older patients with MDS. RIC regimens might also be of interest in patients with relapse after a conventional transplant, particularly, if debulking with chemotherapy before transplantation is successful. The field is developing rapidly.[5-8]

Kroger et al. showed a RFS of 12% at two years among 12 patients with high-risk MDS after RIC HCT from related (n=5) or unrelated HLA-matched (n=7) donors.[19] A report on 37 AML/MDS patients (median age 57 years) transplanted in Spain showed a 1-year NRM of 5%, and RFS of 66% for the entire cohort.[6] A recent update by Stuart et al. on RIC transplants from HLA-matched unrelated donors includes 78 patients with MDS/sAML. These patients were conditioned with fludarabine plus 200 cGy of TBI.[20] Graft failure and disease progression were identified as significant problems, particularly among patients with more advanced MDS and among patients transplanted from unrelated donors.[5] One-year survival was 25% for all patients, and about 40% for good-risk patients. Parker et al reported on 24 patients prepared with a RIC regimen and observed a 2-year RFS of 39%.[7] Similar results have been reported by Martins et al.[6] It is important to point out, however, that a "plateau" may not yet have been reached in these trials. Thus, RIC regimens are of interest for the preparation of patients with MDS. However, additional work is required to secure sustained engraftment, particularly with the use of unrelated donors.

Autologous HCT

Autologous HCT is associated with lower TRM than allogeneic transplants and holds promise where a "pure" population of hemopoietic stem cells can be obtained. The EBMT reported results in 79 patients with MDS and showed a 2-year RFS of 28% after autologous HCT.[21] NRM was 39% in patients >40 years of age. These results were restricted to patients who achieved complete remissions after induction chemotherapy. Wattel et al. prospectively assessed feasibility of autologous HCT (either with bone marrow or PBPC) after conditioning with BU/CY in 24 of 39 patients who achieved a complete remission after induction chemotherapy; 50% of the patients were alive 8-55 months after transplantation.[22] Oosterveld et al[23] recently presented results on 159 patients with MDS who had received induction chemotherapy and then were to receive a transplant from an HLA identical sibling if available or, otherwise, an autologous transplant. Among patients who were actually transplanted, the 4-year RFS was 23% for patients with a donor, and 22% for patients without a donor ($P=0.66$). The authors concluded that autologous and allogeneic transplants gave similar results. Thus, these data suggest that autologous HCT for MDS can result in long lasting remission and should be considered in

patients who have achieved a chemotherapy-induced remission if there is no possibility of allogeneic HCT.

CONCLUSIONS

Patients with high-risk MDS who have suitably HLA-matched related or unrelated donors should be transplanted early in their disease course. Patients with less advanced MDS by FAB criteria (<5% marrow blasts) but with high-risk IPSS cytogenetic findings or severe multilineage cytopenias according to WHO, and transfusion dependence also should be considered for early transplantation. Patients with MDS with low-risk IPSS cytogenetic features and without severe cytopenias may do well for extended periods of time with more conservative management. HCT can be carried out successfully, even in the seventh decade of life. The use of PBPC may offer an advantage over marrow cells. The place of RIC transplants, other than for patients of advanced age (older than 60 or 65 years), in our opinion, remains to be determined. Investigations in the future will focus on identification of additional prognostic parameters allowing to predict prognosis as well as on determination of the optimal timing of HCT.[24,25]

REFERENCES

1. Bennett JM, Catovsky D, Daniel MT, Flandrin G, Galton DAG, Gralnick HR, Sultan C, The French-American-British (FAB) Co-Operative Group. Proposals for the classification of the myelodysplastic syndromes. *Br J Haematol*. 1982;51:189–199.
2. Harris NL, Jaffe ES, Diebold J, Flandrin G, Muller-Hermelink HK, Vardiman J, Lister TA, Bloomfield CD. World Health Organization classification of neoplastic diseases of the hematopoietic and lymphoid tissues: report of the clinical advisory committee meeting–Airlie House, Virginia, November 1997. *J Clin Oncol*. 1999;17:3835–3849.
3. Greenberg P, Cox C, LeBeau MM, Fenaux P, Morel P, Sanz G, Sanz M, Vallespi T, Hamblin T, Oscier D, Ohyashiki K, Toyama K, Aul C, Mufti G, Bennett J. International scoring system for evaluating prognosis in myelodysplastic syndromes (published erratum appears in *Blood*. 1998; 91:1100). *Blood*. 1997;89: 2079–2088.
4. Cutler CS, Lee SJ, Greenberg P, Deeg HJ, Pérez WS, Anasetti C, Bolwell BJ, Cairo MS, Gale RP, Klein JP, Lazarus HM, Liesveld JL, McCarthy PL, Milone GA, Rizzo JD, Schultz KR, Trigg ME, Keating A, Weisdorf DJ, Antin JH, Horowitz MM. A decision analysis of allogeneic bone marrow transplantation for the myelodysplastic syndromes: delayed transplantation for low risk myelodysplasia is associated with improved outcome. *Blood* (in press).
5. Stuart MJ, Cao TM, Sandmaier BM, Hegenbart U, Maris M, Agura E, Chauncey TR, Maloney DG, Pulsipher MA, Wong R, Niederwieser DW, Blume KG, Storb RF. Efficacy of non-myeloablative allogeneic transplant for patients with myelodysplastic syndrome (MDS) and myeloproliferative disorders (MPD) (except chronic myelogenous leukemia). *Blood*. 2003;102 (Part 1):185a, #644 (Abstract).
6. Martino R, Caballero MD, Simón JA, Canals C, Solano C, Urbano-Ispízua A, Bargay J, Léon A, Sarrá J, Sanz GF, Moraleda JM, Brunet S, San Miguel J, Sierra J, AML and alloPBSCT Subcommittees of the Spanish Group for Hematopoietic Transplantation. Evidence for a graft-versus-leukemia effect after allogeneic peripheral blood stem cell transplantation with reduced-intensity conditioning in acute myelogenous leukemia and myelodysplastic syndromes. *Blood*. 2002;100:2243–2245.
7. Parker JE, Shafi T, Pagliuca A, Mijovic A, Devereux S, Potter M, Prentice HG, Garg M, Yin JA, Byrne J, Russell NH, Mufti GJ. Allogeneic stem cell transplantation in the myelodysplastic syndromes: interim results of outcome following reduced-intensity conditioning compared with standard preparative regimens. *Br J Haematol*. 2002;119:144–154.
8. Maris M, Storb R. The transplantation of hematopoietic stem cells after non-myeloablative conditioning: A cellular therapeutic approach to hematologic and genetic diseases. *Immunologic Research*. 2003;28:13–24.
9. Scott BL, Deeg HJ, Appelbaum FR. Pre-transplant induction chemotherapy and post-transplant relapse in patients with advanced MDS. *Blood*. 2003;102 (Part 1):152A, 523 (Abstract).
10. Deeg HJ, Storer B, Slattery JT, Anasetti C, Doney KC, Hansen JA, Kiem H-P, Martin PJ, Petersdorf E, Radich JP, Sanders JE, Shulman HM, Warren EH, Witherspoon RP, Bryant EM, Chauncey TR, Getzendaner L, Storb R, Appelbaum FR. Conditioning with targeted busulfan and cyclophosphamide for hemopoietic stem cell transplantation from related and unrelated donors in patients with myelodysplastic syndrome. *Blood*. 2002;100:1201–1207.
11. Sierra J, Pérez WS, Rozman C, Carreras E, Klein JP, Rizzo JD, Davies SM, Lazarus HM, Bredeson CN, Marks DI, Canals C, Boogaerts MA, Goldman J, Champlin RE, Keating A, Weisdorf DJ, de Witte TM, Horowitz MM. Bone marrow transplantation from HLA-identical siblings as treatment for myelodysplasia. *Blood*. 2002;100:1997–2004.
12. Guardiola P, Runde V, Bacigalupo A, Ruutu T, Locatelli F, Boogaerts MA, Pagliuca A, Cornelissen JJ, Schouten HC, Carreras E, Finke J, van Biezen A, Brand R, Niederwieser D, Gluckman E, de Witte TM, Subcommittee for Myelodysplastic Syndromes of the Chronic Leukaemia Working Group of the European Blood and Marrow Transplantation Group. Retrospective comparison of bone marrow and granulocyte colony-stimulating factor-mobilized peripheral blood progenitor cells for allogeneic stem cell transplantation using HLA identical sibling donors in myelodysplastic syndromes. *Blood*. 2002;99:4370–4378.
13. Castro-Malaspina H, Harris RE, Gajewski J, Ramsay N, Collins R, Dharan B, King R, Deeg HJ. Unrelated donor marrow transplantation for myelodysplastic syndromes: outcome analysis in 510 transplants facilitated by the National Marrow Donor Program. *Blood*. 2002; 99:1943–1951.
14. Runde V, de Witte T, Arnold R, Gratwohl A, Hermans J, van Biezen A, Niederwieser D, Labopin M, Walter-Noel MP, Bacigalupo A, Jacobsen N, Ljungman P, Carreras E, Kolb HJ, Aul C, Apperley J. Bone marrow transplantation from HLA-identical siblings as first-line treatment in patients with myelodysplastic syndromes: early transplantation is associated with improved outcome. Chronic Leukemia Working Party of the European Group for Blood and Marrow Transplantation. *Bone Marrow Transplant*. 1998;21:255–261.
15. de Witte T, Pikkemaat F, Hermans J, van Biezen A, Mackinnan S, Cornelissen J, Gratwohl A, Delforge M, Iriondo A, Kuentz M, Harousseau J, Fauser A, Wandt H, Runde V, Niederwieser D, Apperley J. Genotypically nonidentical related donors for transplantation of patients with myelodysplastic syndromes: comparison with unrelated donor transplantation and autologous stem cell transplantation. *Leukemia*. 2001;15:1878–1884.
16. Jurado M, Deeg HJ, Storer B, Anasetti C, Anderson JE, Bryant E, Chauncey T, Doney K, Flowers MED, Hansen J, Martin PJ, Nash RA, Petersdorf E, Radich J, Sale G, Sandmaier BM, Storb R, Wade J, Witherspoon R, Appelbaum FR. Hematopoietic stem cell transplantation for advanced myelodysplastic syndrome after conditioning with busulfan and fractionated total body irradiation is associated with low relapse rate but considerable nonrelapse mortality. *Biol Blood Marrow Transplant*. 2002;8:161–169.
17. Bornhäuser M, Storer B, Slattery JT, Appelbaum FR, Deeg HJ, Hansen J, Martin PJ, McDonald GB, Nichols G, Radich J, Woolfrey A, Jenke A, Schleyer E, Thiede C, Ehninger G, Anasetti C. Conditioning with fludarabine and targeted busulfan for transplantation of allogeneic hematopoietic stem cells. *Blood*. 2003;102:820–826.
18. Russell JA, Tran HT, Quinlan D, Chaudhry A, Duggan P, Brown C, Stewart D, Ruether JD, Morris D, Glick S, Gyonyor E, Andersson BS. Once-daily intravenous busulfan given with fludarabine as conditioning for allogeneic stem cell transplantation: study of pharmacokinetics and early clinical outcomes. *Biol Blood Marrow Transplant*. 2002;8:468–476.

19. Kroger N, Schetelig J, Zabelina T, Kruger W, Renges H, Stute N, Schrum J, Kabisch H, Siegert W, Zander AR. A fludarabine-based dose-reduced conditioning regimen followed by allogeneic stem cell transplantation from related or unrelated donors in patients with myelodysplastic syndrome. *Bone Marrow Transplant*. 2001;28:643–647.
20. Maris MB, Niederwieser D, Sandmaier BM, Storer B, Stuart M, Maloney D, Petersdorf E, McSweeney P, Pulsipher M, Woolfrey A, Chauncey T, Agura E, Heimfeld S, Slattery J, Hegenbart U, Anasetti C, Blume K, Storb R. HLA-matched unrelated donor hematopoietic cell transplantation after nonmyeloablative conditioning for patients with hematologic malignancies. *Blood*. 2003;102:2021–2030.
21. de Witte T, van Biezen A, Hermans J, Labopin M, Runde V, Or R, Meloni G, Mauri SB, Carella A, Apperley J, Gratwohl A, Laporte J-P. Autologous bone marrow transplantation for patients with myelodysplastic syndrome (MDS) or acute myeloid leukemia following MDS. *Blood*. 1997;90:3853-3857.
22. Wattel E, Solary E, Leleu X, Dreyfus F, Brion A, Jouet JP, Hoang-Ngoc L, Maloisel F, Guerci A, Rochant H, Gratecos N, Casassus P, Janvier M, Brice P, Lepelley P, Fenaux P. A prospective study of autologous bone marrow or peripheral blood stem cell transplantation after intensive chemotherapy in myelodysplastic syndromes. *Leukemia*. 1999;13:524–529.
23. Oosterveld M, Suciu S, Verhoef G, Labar B, Belhabri A, Aul C, Selleslag D, Ferrant A, Wijermans P, Mandelli F, Amadori S, Jehn U, Muus P, Zittoun R, Hess U, Anak O, Beeldens F, Willemze R, de Witte T. The presence of an HLA-identical sibling donor has no impact on outcome of patients with high-risk MDS or secondary AML (sAML) treated with intensive chemotherapy followed by transplantation: results of a prospective study of the EORTC, EBMT, SAKK and GIMEMA Leukemia Groups (EORTC study 06921). *Leukemia*. 2003;17:859–868.
24. Cutler C, Lee S, Greenberg P, Deeg J, Antin J, Perez W, Horowitz M. A decision analysis of allogeneic stem cell transplantation for MDS: delayed transplantation for low risk MDS is associated with improved outcome. *Blood*. 2002;100 (Part 1):74a, #270 (Abstract).
25. Benesch M, Wells DA, Leisenring W, Loken MR, Myerson D, Deeg HJ. Prognostic significance of pretransplant multidimensional flow cytometric parameters for posttransplant survival and relapse in 111 patients with myelodysplastic syndrome (MDS). *Blood*. 2002;100 (Part 1):97a, #358 (Abstract).

Patients: Your Help is Needed!

We would like to invite you to participate in selected study groups and share your experience living with MDS and the quality-of-life issues that you face. The information we develop will be used to educate healthcare professionals about MDS patients' needs in dealing with MDS. The number of groups and their location will depend upon the responses we receive.

Please join us in this most important endeavor. Further developments will be posted on our website or for more information contact the Patient Liaison at 1-800-MDS-0839.

MDS

About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted seven international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, and France. The Eighth International Symposium is being held May, 2005 in Nagasaki, Japan.

One major role of the Foundation is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available programs, sharing of new research and treatment options, and extension of educational support to both physicians and patients. Ultimately, we hope to provide funding and oversight for international studies in MDS.

In response to the needs expressed by patients, families, and physicians, we have established patient advocacy groups.

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.

Our Website

The MDS Foundation Web page is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our Web site.

The Website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them.

We welcome your suggestions.

Please visit us at *http://www.mds-foundation.org*

A Patient's Story

Andrea Lacey
Dorset, United Kingdom

In January 1994, I went to my doctor to have a medical so that I could get some life insurance. To my surprise he told me I was anaemic, had a heart murmur and was generally unwell. He asked me to go for some blood tests and this was followed with more and more tests, until I was sent for a bone marrow test. This was followed by more bone marrow tests. After one of the tests I was asked to ring for the results from work. My GP told me he didn't think I had leukaemia, but that it could be. I was devastated, at work and so scared – I was only 29.

Anyway, myelodysplasia was diagnosed and more explicitly RAEB-t. The transition part was already on the move! My consultant at the local hospital told me my only chance of survival was a bone marrow transplant. At this point I was beginning to realise how very rare MDS and I knew it was the first time my consultant had been involved in treating somebody so young with the illness. I trawled the internet to try and find a story or case study where some one had managed to come out the other end alive, but there wasn't one. Having checked the net again recently (2004) the picture isn't much less bleak.

I can't begin to explain the ups and the downs, or the desperate feeling of misery I felt at that time. From diagnosis to the treatment there was about 4 months and this was the amount of time needed to find a donor and come try to come to terms with what was going on. Following each hospital visit I would exist in a shell-shocked state – I can't think of the words to explain the feeling, but remember it well. This would last for a few days and then I was able to separate (to some extent) that feeling from my every thought and would try to become quite positive.

I have one brother who at the time was 25 (5 years younger than me) and following tests we were told he was a suitable match to be my bone marrow donor. This meant that I started the treatment with 40% chance of survival and knowing where the starting point was meant I was able to start the challenge to live. I worked out that as most people with MDS are older I stood a very good chance of being part of the 40% that did live. My partner and I bought loads of fruit, vegetables, self-help books, went on long walks and in fact did everything we could to give me a good start for the treatment. I worked on the basis that it would only be a couple of weeks in isolation and then about 6 months off work and that would be it; a very small amount of time out of a lifetime!

Actually it didn't work out like that at all! The transplant treatment wasn't successful and there were still some MDS cells that hadn't been killed by the total body irradiation and chemo. In fact, to be more precise I think it was probably just the one rogue cell! My consultant explained that a second transplant wasn't an option because of the damaging effects that the chemotherapy had already had on my body and so it was a case of damage limitation – trying to control what was happening and buying enough time in case a new treatment came out.

There is so much more I could say about this time and although it was all so desperate, there were some happy times and some very funny times. There isn't room for these here, but maybe I will write 'that' book one-day. To cut a long story short my consultant tried for a year to keep me going with maintenance treatment. This involved bags of blood and so many types of drugs; at one point he thought the cancer had gone. But, in May 1995 the MDS was back and I started a treatment using stem cells and leucocytes that were donated by my ever patient brother. This treatment seemed to work and in November a bone marrow test showed 100% my brother's bone marrow. That night we had a party!

By December I was beginning to feel rough again and developed pleurisy whilst on a trip to France. I had a bone marrow test in Jan 1996 and this showed that I had Acute Myeloid Leukaemia. My consultant explained that I couldn't have another transplant because the effects would be too damaging to the body; the only option was more chemo. So I went back into isolation and this time I didn't think I would be coming out, but I was determined I didn't want to die. I had 5% chance of survival. Mega doses of chemotherapy were followed by weeks and weeks in isolation and then more chemo and more isolation. I not only lost all my hair and nails again, but also the skin around my teeth and in my mouth – I had to be drip-fed and so many other side effects. On the up-side though, I had a morphine pump, the effects of which were really rather pleasant!

I had reached a horrible place. My consultant and I discussed the options. We came to an understanding that whilst I kept breathing he would keep treating me. However, the options weren't great – we could do nothing and let the ever returning leukaemia take its course, have more chemo with little realistic chance of survival, or try a brand new treatment that hadn't actually been successful yet. That was the

option I went for, the donor lymphocyte infusion–not a lot to lose by that time.

During my illness I had continued studying for my degree with the Open University believing that if I stopped my studies I would feel like I was waiting to die. Anyway, I left hospital in the April for my graduation and then had my donor lymphocyte treatment in May. From here life was a circle of bone marrow tests, blood infusions, drug infusions, tablets (32 different ones at one point!), bronchitis, pneumonia and so on. It was in February 1997 that I finally got the result I wanted–100% my brother's bone marrow!!

Seven years on I am absolutely fine and living life to the full. The only side effects are a premature menopause and I have had cataracts removed in both eyes–not bad I would say considering what had gone before. When I began to get better I decided to do both a counselling and teaching course. Since then I have been working in adult education and using my degree to teach psychology. I now also teach psychology for the Open University and also at the local university. My partner and I didn't continue our relationship, but I am now living very happily with a lovely man who I met through my brother and we have two cats! My brother lives twelve houses away and is chief in charge of looking after the cats when we are on holiday. We came back from Tunisia last Saturday and will be in Mauritius in June!

MDS patient Andrea Lacey with her donor brother.

Share Your Stories

The Foundation would like to invite patients and their families to share their stories with others in the MDS community. Living with MDS poses challenges and many of you have stories that provide hope to others. Please contact the Foundation if you would like us to publish your story!!

Be a Bone Marrow Donor

For those patients diagnosed with a fatal blood disorder, bone marrow transplantation (BMT) is often the only chance of survival. Related donors provide suitable matches only 33 percent of the time. This leaves nearly 70 percent of patients without a match. The need is especially critical in racial and ethnic minority groups.

Registering as a donor is simple. A blood sample is all you need to enter your tissue type into the National Marrow Donor Program (NMDP) computerized registry. If you are in good health and between the ages of 18 and 55, you can contact NMDP at 1-800-MARROW-2. They will send additional information, including the NMDP center nearest you. Give the Gift of Life!

MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet the new HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient's names to the Registry. The Registry is located at the MDS Foundation's Statistical Center at the University of Rochester Cancer center. The Foundation looks forward to building the Patient Registry with our Centers of Excellence. If you would like to become a Center of Excellence, please contact The Foundation at the address below.

The MDS Foundation
36 Front Street, PO Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839 within the US
Outside the US only: 1-609-298-6746
Fax: 1-609-298-0590

MDS Educational Resources for Clinicians

The Myelodysplastic Syndromes Pathobiology and Clinical Management
(Basic and Clinical Oncology Series/27)

Edited by:
John M. Bennett
James P. Wilmot Cancer Center of the University of Rochester, Rochester, New York, U.S.A.

May 2002/528 pp., illus., ISBN: 0-8247-0782-6/$165.00
Marcel Dekkar, Inc. 800-228-1160
When ordering, use code PAO50203

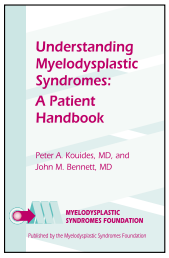
This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care that improve patient survival and enhance quality of life.

A NEW CME PROGRAM AVAILABLE IN CD-ROM FORMAT

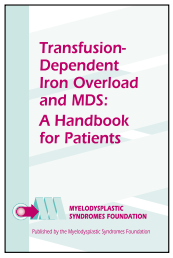
The Myelodysplastic Syndromes: Controversies in Classification and An Optimistic Look at New Treatment Options.

You may request this program by contacting the Foundation at 800-MDS-0839 or by logging on to our website: www.mds-foundation.org.

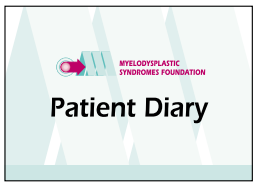
PATIENT INFORMATION AND EDUCATIONAL MATERIALS AVAILABLE FROM THE MDS FOUNDATION



A.



B.



C.

A. Understanding Myelodysplastic Syndromes: A Patient Handbook
Peter A. Kouides, MD; John M. Bennett, MD

B. Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
Published by The Myelodysplastic Syndromes Foundation

C. Patient Diary
Published by
The Myelodysplastic Syndromes Foundation

All of these materials are available free of charge from the Foundation.

Blood & Marrow Transplant Newsletter

Blood & Marrow Transplant Newsletter is published four times annually by BMT InfoNet.

To subscribe, contact:

BMT InfoNet
2900 Skokie Valley Road, Suite B
Highland Park, IL 60035

Toll free: 888-597-7674
Tel: 847-433-3313 Fax: 847-433-4599

E-Mail: help@bmtinfonet.org
Web: www.bmtinfonet.org

Patient Referrals

Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality of life can be enhanced.

If you would like information about treatment options, research, or quality of life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to MDS Centers of Excellence.

Please contact us at:

1-800-MDS-0839 (phone) or 609-298-0590 (fax). Outside the US please call 609-298-1035.

You can also visit our Web site at *http:www.mds-foundation.org.*

MDS Centers of Excellence

Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? To be recognized as a Center of Excellence, an institution must have the following:

- An established university (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board–approved clinical trials
- Documentation of peer-reviewed publications in the field
- The ability and intention to register patients in the MDS International Registry database

Please contact the Foundation for further information and an application form for your center.

The following centers have qualified as MDS Centers of Excellence:

UNITED STATES

Barbara Ann Karmanos Cancer Institute
Wayne State University
Detroit, Michigan
Esteban Abella, MD; Charles A. Schiffer, MD

The Cancer Center of Hackensack
University Medical Center
Hackensack, New Jersey
Stuart Goldberg, MD

Cedars-Sinai Medical Center
UCLA School of Medicine
Los Angeles, California
H. Phillip Koeffler, MD

City of Hope National Medical Center
Duarte, California
Stephen J. Forman, MD

Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD

Cleveland Clinic Foundation
Taussig Cancer Center
Cleveland, Ohio
Jaroslaw Maciejewski, MD

Duke University
Duke University Medical Center
Durham, North Carolina
Carlos M. deCastro, MD

Fred Hutchinson Cancer Research Center
Seattle, Washington
Joachim Deeg, MD

Indiana University
Indiana University Medical Center
Indianapolis, Indiana
Larry Cripe, MD

Johns Hopkins Oncology Center
Johns Hopkins Institutions
Baltimore, Maryland
Steven D. Gore, MD

Mayo Clinic
Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

Mayo Clinic
Rochester, Minnesota
Louis Letendre, MD

MCP Hahnemann University
Philadelphia, Pennsylvania
Emmanuel C. Besa, MD

Medical College of Wisconsin
Bone Marrow Transplant Program
Milwaukee, Wisconsin
David H. Vesole, MD, PhD, FACP

Memorial Sloan-Kettering Cancer Center
New York, New York
Stephen D. Nimer, MD

National Heart Lung and Blood Institute
Bethesda, MD
Elaine Sloand, MD

New York Medical College/
Westchester Medical Center
Zalmen A. Arlin Cancer Center
Valhalla, NY
Karen Seiter, MD

New York Presbyterian Hospital
Columbia College of Physicians and Surgeons
New York, New York
Charles Hesdorffer, MD

New York University School of Medicine
North Shore University Hospital
Manhasset, New York
Steven L. Allen, MD

Oregon Cancer Center at
Oregon Health Science University
Portland, Oregon
Grover Bagby, MD

Roswell Park Cancer Center
Buffalo, New York
Maria R. Baer, MD

Rush Cancer Institute
Rush–Presbyterian– St. Luke's Medical Center
Chicago, Illinois
Azra Raza, MD

Seattle Cancer Care Alliance
University of Washington
Seattle, Washington
John A. Thompson, MD

Southwest Regional Cancer Center
Austin, Texas
Richard Helmer, III, MD

Stanford University
Stanford University Medical Center
Stanford, California
Peter L. Greenberg, MD

St. Jude's Childrens' Research Hospital
Memphis, Tennessee
Gregory Hale, MD

Tufts University School of Medicine
New England Medical Center
Boston, Massachusetts
Geoffrey Chan, MD

University of Alabama at Birmingham
Comprehensive Cancer Center
Birmingham, Alabama
Peter Emanuel, MD

University of Arizona
Arizona Cancer Center
Tucson, Arizona
Daruka Mahadevan, MD, PhD

University of Chicago
University of Chicago Medical Center
Chicago, Illinois
Richard A. Larson, MD

University of Nebraska
University of Nebraska Medical Center
Omaha, Nebraska
Lori Maness, MD

University of Pennsylvania
University of Pennsylvania Cancer Center
Philadelphia, Pennsylvania
Selina Luger, MD

University of Rochester
University of Rochester Cancer Center
Rochester, New York
John M. Bennett, MD

University of South Florida
H. Lee Moffitt Cancer Center and Research Institute
Tampa, Florida
Alan F. List, MD

University of Texas
MD Anderson Cancer Center
Houston, Texas
Elihu H. Estey, MD

Washington University School of Medicine
Barnard Cancer Center
St. Louis, Missouri
John F. DiPersio, MD, PhD

Weill Medical College of Cornell University
New York Presbyterian Hospital
New York, New York
Eric J. Feldman, MD

The Western Pennsylvania Cancer Institute
Pittsburgh, Pennsylvania
Richard K. Shadduck, MD

William Beaumont Hospital Cancer Center
Royal Oak, MI
Ishmael Jaiyesimi, MD

OUTSIDE THE UNITED STATES

A.C. Camargo Hospital – Cancer Center
São Paulo, Brazil
Luiz Fernando Lopes, MD, PhD

Academic Hospital
Free University Amsterdam
Amsterdam, The Netherlands
G.J. Ossenkoppele, MD, PhD

Athens University, Evangelismos Hospital
Athens, Greece
Theofanis Economopoulos, MD

Casa Sollievo Della Sofferenza Hospital
S. Giovanni Rotondo, Italy
Pelligrino Musto, MD

Hannover Medical School
Medizinische Hochschule Hannover
Hannover, Germany
Prof. Dr. Arnold Ganser

Heinrich-Heine University Düsseldorf
University Hospital
Düsseldorf, Germany
Ulrich Germing, MD

Hôpital Saint Louis, University Paris VII
Paris, France
Prof. Christine Chomienne

Hospital Universitario de Salamanca
Salamanca, Spain
Prof. Jesus F. San Miguel

Hospital Universitario La Fe
Valencia, Spain
Miguel A. Sanz, MD, PhD

Institute of Hematology and Blood Transfusion
Prague, Czech Republic
Jaroslav Čermák, MD, PhD

Jagiellonian University
Collegium Medicum
Krakow, Poland
Aleksander Skotnicki, MD, PhD

Johann Wolfgang Goethe University
Frankfurt Main, Germany
Wolf-Karsten Hofmann, MD

Karolinska Institute
Huddinge University Hospital
Stockholm, Sweden
Eva Hellström-Lindberg, MD, PhD

King Chulalongkorn Memorial Hospital
Pathumwan, Bangkok, Thailand
Tanin Intragumtornchai, MD

King's College Hospital
Guy's Kings Thomas School of Medicine
London, England
Prof. Ghulam J. Mufti

Kyoto University Hospital
Kyoto, Japan
Takashi Uchiyama, MD

Ludwig Maximilians University
Munich, Germany
Torsten Haferlach, MD

Nagasaki University Hospital
School of Medicine
Atomic Bomb Disease Institute
Nagasaki City, Japan
Prof. Masao Tomonaga

Odense University Hospital
The University of Southern Denmark
Odense, Denmark
Gitte Birk Kerndrup, MD

Patras University Hospital
Patras, Greece
Nicholas C. Zoumbos, MD

Peter MacCallum Cancer Institute
University of Melbourne
East Melbourne, Victoria, Australia
John F. Seymour, MD

Rabin Medical Center–Hasharon Hospital
Tel Aviv University–Sackler School of Medicine
Petah-Tikva, Israel
Moshe Mittelman, MD

Saitama Medical School Hospital
Morohongo, Iruma, Japan
Akira Matsuda, MD

Services D'Hematologie Hôpital Cochin
University Paris V Service
Paris, France
Prof. Francois Dreyfus, PU-PH

Service des maladies de Sang
Centre Hospitalier, Universitaire of Lille
Lille, France
Prof. Pierre Fenaux

St. Johannes Hospital
Heinrich-Heine University
Duisburg, Germany
Carlo Aul, MD, PhD

The Royal Bournemouth Hospital
Bournemouth, United Kingdom
Sally Killick, MD

Tokyo Medical College
Tokyo, Japan
Kazuma Ohyashiki, MD

Universidade Federal de Ceará
Ceará, Brazil
Fernando Barroso Duarte, MD

University of Aarhus
The University Hospital
Aarhus, Denmark
Professor Johan Lanng Nielsen

University of Athens, Laikon Hospital
Athens, Greece
Nora Viniou, MD

University of Cape Town, Groote Schuur Hospital
Cape Town, Cape South Africa
Nicolas Novitzky, MD, PhD

University of Dundee Medical School
Dundee Teaching Hospital
Dundee, Scotland
David T. Bowen, MD

University of Florence, Azienda OSP Careggi
Florence Italy
Alberto Grossi, MD

University of Freiburg Medical Center
Freiburg, Germany
Michael Lübbert, MD, PhD

Universität Hamburg
Hamburg, Germany
Nicolaus Kröger, MD, PhD

University Hospital of Innsbruck
Innsbruck, Austria
Prim. Univ. Prof. Dr. Franz Schmalzl

University of Nijmegen
University Hospital St. Radboud
Nijmegen, The Netherlands
Theo J.M. deWitte, MD, PhD

University of Pavia Medical School
IRCCS Policlinico San Matteo
Pavia, Italy
Mario Cazzola, MD

University of Tasmania
Royal Hobart Hospital
Hobart, Tasmania, Australia
Prof. Raymond M. Lowenthal, MD, FRCP, FRACP

University of Toronto, Hospital for Sick Children
Toronto, Ontario, Canada
Yigal Dror, MD

University Tor Vergata, Ospedale S. Eugenio
Roma, Italy
Sergio Amadori, MD

University of Vienna
Vienna, Austria
Peter Valent, MD

ASH Highlights

San Diego, California
December 6, 2003

Chairman Receives Investigator Award

We are pleased to announce that our Chairman, John Bennett, MD, was selected to receive the Inaugural Celgene Hematology Career Achievement Award. An independent committee of 5 of Dr. Bennett's colleagues in hematology/oncology selected him for this award from among several nominees. In addition to receiving a crystal award, he was awarded a grant from Celgene to further research and development in MDS.

Dr. Bennett accepts his award during the ASH annual meeting in San Diego at a special event hosted by Celgene Corporation.

Jerome B. Zeldis, MD, PhD (left), Chief Medical Officer/VP Medical Affairs, Celgene Corporation

John M. Bennett, MD (center), Professor of Medicine, Laboratory Medicine and Pathology, Emeritus University of Rochester, James P. Wilmot Cancer Center

Alan F. List, MD, (right), Director, Hematologic Malignancies Program, University of South Florida, H. Lee Moffitt Cancer Center

John M. Bennett, MD, Award Recipient (left): Career in Clinical Hematology Achievement

Robert Z. Orlowski, MD, PhD, Award Recipient (right): Young Investigator for Achievement in Clinical Hematology Research

Dr. Bennett with his wife Carol

Thank You to Our Pharmaceutical Partners

We would like to thank our pharmaceutical partners for their support of the Foundation and its work. They have contributed in the form of unrestricted educational grants, which support not only this newsletter but also the development of the MDS home page on the World Wide Web, the Centers of Excellence program, continuing medical education programs, the Patient Registry, and the dissemination of patient information.

SAVE THE DATE:
MONDAY, AUGUST 9, 2004!

The MDS Foundation Inaugural Charity Golf Tournament

The MDS Foundation is pleased to announce it's first annual charity golf tournament to be held August 9, 2004 at the Olde York Country Club, Old York Road, Chesterfield, NJ. Olde York Country Club, designed by Gary Player Design Group, is the 10th highest ranked course in the state. Olde York Country Club was awarded the 1999 Best Private Golf Course by The New Jersey Golf Owners Association.

Everyone is welcome to participate in this worthwhile fundraiser, the proceeds of which will benefit support and education in the myelodysplastic syndromes for physicians and patients. Please join us for a day of great golf, food and fun!

Interested players and sponsors are invited to contact The MDS Foundation at 1-800-MDS-0839 or visit our website at www.mds-foundation.org.

Foundation Plans International Symposia through 2007

The MDS Foundation has approved applications for the next two International Symposia. These symposia are scheduled for 2005 in Nagasaki, Japan and 2007 in Florence, Italy.

Eighth International Symposium
May 12–15, 2005
Nagasaki, Japan
Chairman:
Professor Masao Tomonaga

Ninth International Symposium
Spring 2007
Florence, Italy
Chairman: Mario Cazzola, MD

A Living Endowment

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

A commitment to donate to the Foundation on occasions of loss, birthdays and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and The MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

The MDS Foundation is grateful for community support. Our work as a non-profit organization depends on public funding.

If you would like to contribute in this way, please write to us at:

36 Front Street
P.O. Box 353
Crosswicks, NJ 08515

or call us at 1-800-MDS-0839.

Patient Services

AirLifeLine: For nearly 25 years, **AirLifeLine** has helped people overcome the obstacle of distance and access to healthcare. Through a nationwide network of 1,500 volunteer pilots, AirLifeLine coordinates *free* air transportation for people in need. AirLifeLine's generous and compassionate volunteer pilots—men and women from all 50 states with a wide variety of backgrounds—donate flights in their personal general aviation aircraft. Passengers fly *totally free*, as often as necessary and for as long as needed, to reach medical care or for numerous other humanitarian needs. Since 1978, and AirLifeLine volunteer pilots have flown over 30,000 missions. In 2002, AirLifeLine volunteer pilots provided free air transportation for nearly 9,500 passengers (men, women, and children), saving them over $4 million in commercial travel expenses, helping them reach medical treatment that would otherwise be inaccessible.

Although the vast majority of its passengers fly for medical reasons, AirLifeLine pilots also offer free flights for other humanitarian reasons. Each summer, AirLifeLine's volunteer pilots distribute the children from Chernobyl to host homes across the U.S. for a two-month summer respite. They also transport hundreds of children to health-related summer camps each year. And, within 48 hours of the terrorist attacks on 9/11/01 and while most aircraft were still grounded, AirLifeLine volunteer pilots were in the air transporting emergency service personnel, disaster victims, blood and medical supplies in support of disaster relief efforts in New York City and Washington, D.C.

AirLifeLine is a non-profit 501 (c) (3) organization that relies 100% on the generosity of volunteer pilots, as well as individual, corporate, and foundation contributions. AirLifeLine is the oldest and largest national volunteer pilot organization in the United States. For more information about AirLifeLine, visit www.AirLifeLine.org or call toll-free (877) AIR LIFE (877-247-5433).

RESOURCE DATABASE INFORMATION:

Agency Name: **AirLifeLine**

National Office
5775 Wayzata Blvd., Suite 700
Minneapolis, MN 55416
Phone: (952) 582-2980
Toll-free: (877) 727-7728
Fax: (952) 546-5885
Call here for: Outreach, development and administrative inquiries

Operations Center
50 Fullerton Ct., Suite 200
Sacramento, CA 95825
Phone: (916) 641-7800
Toll-free: (877) AIR LIFE (247-5433)
Fax: (916) 641-0600
Call here for: Passenger/pilot inquiries

TYY: Not available, but we can use a relay operator.

Website: www.AirLifeLine.org

E-mail: Info@AirLifeLine.org

Administrator: Randy Quast, President & Volunteer Pilot

Contact person for agency information:
Ginger Buxa, Director of Outreach
Ginger@AirLifeLine.org or (877) 727-7728

Program Description: Since 1978, AirLifeLine has helped to ensure equal access to healthcare and improve the quality of life for thousands of people throughout the United States by coordinating free air transportation for those in need.

Services Provided: AirLifeLine coordinates the following services:

1. Transporting people with medical and financial need to reach medical care far from home.
2. Transporting people with time-critical needs associated with a transplant procedure.
3. Transporting precious cargo such as organs, blood, tissue and medical supplies.
4. Providing free air support for disaster relief efforts in times of crisis.
5. Providing flights for numerous other humanitarian needs.

Funding Source: AirLifeLine is a national non-profit 501(c)(3), charitable organization funded entirely by tax deductible donations from individuals, foundations and corporations and the generosity of our volunteer pilots who donate the direct costs of every flight. Over 94% of all support and contributions donated to AirLifeLine goes directly to program services.

Volunteer Opportunities: AirLifeLine is currently seeking volunteer pilots in many areas of the country. For more information, visit www.AirLifeLine.org or call (877) AIR LIFE.

Passenger Eligibility: Our volunteer pilots fly passengers free of charge and as often as necessary for diagnosis, treatment, and follow-up care, and for other humanitarian reasons.

1. AirLifeLine passengers must be ambulatory or need little or no assistance to board and exit the aircraft.
2. Passengers must be medically stable and able to fly in an unpressurized aircraft.

3. Passengers must demonstrate financial need.

Application Method:
To request a free flight, just call toll-free (877) AIR-LIFE (877-247-5433). In urgent situations, a coordinator can be paged after normal business hours. Just call (877) AIR LIFE and follow the paging instructions on the voice mail message.

You may also request a flight by visiting www.AirLifeLine.org.

Service Area:
All U.S. states, parts of Canada & Mexico

Cost/Fees: None, but donations accepted

Waiting List:
None, but 1-2 weeks advance notice is preferred

Target group: Anyone with financial need who needs air transportation

Age Range: All

Handicap Access: Somewhat, depending on type and size of aircraft

Languages: English and Spanish

If you need more information for your resource database or website listing, please contact: Ginger Buxa, Director of Outreach, (877) 727-7728, E-Mail: Ginger@AirLifeLine.org

Suzanne Fleischman Memorial Fund for Patient Advocacy

New donations have been made by:

Edward Fleischman, *Prescott, AZ*

Roslyn Raney, *Menlo Park, CA*

Fay Wanetick, *Pittsburgh, PA*

In Memorium

A memorial fund has been established in the name of

Mr. Frank Akins

Donations have been made in Mr. Akin's memory by:

Mark and Nancy Manning, *Fort Mill, SC*

A memorial fund has been established in the name of

Mrs. Levonia Smith Albury

Donations have been made in Mrs. Albury's memory by:

Gerard and Alice Zell, *Hollywood, FL*

A memorial fund has been established in the name of

Mr. George Allen

Donations have been made in Mr. Allen's memory by:

Beverly Allen
Koloa, HI

Karen Allen-Maguire
Ellsworth, ME

Hope Linnehan
Ellsworth, ME

David Yarborough
Stillwater, ME

Joseph and Mary Jordan
Ellsworth, ME

Thomas P. Davis
Arlington, VA

Phil and Grace Shea
Ellsworth, ME

Richard Merrill
Hancock, ME

Kenneth and Diane Stewart
Eastbrook, ME

Reta Dunn and Family
Ellsworth, ME

Simutronics Corp.
St. Charles, MO

Michael Saunders
Trenton, ME

Eugene and Karen Morton
Wall, NJ

Sargent Real Estate
Ellsworth, ME

Delmont and Elizabeth Merrill
Ellsworth, ME

Susan Kendall
Encino, CA

Colwell Family
Ellsworth, ME

Dale Scott
Waldoboro, ME

Douglas and Joan Smith
Franklin, ME

Joyce M. Johnston
Ellsworth, ME

Julia Browne
Vassalboro, MI

Brookland Products, Ltd.
Nova Scotia

James and Kim Wadman
Ellsworth, ME

L.S. Robinson Co.
Southwest Harbor, ME

Thomas O. Batey
Koloa, HI

A memorial fund has been established in the name of

Ms. Wendy Ames

Donations have been made in Ms. Ame's memory by:

Nancy Valentage
Webster, NY

Steven and Nancy Herbert
Williamson, NY

Heidi Miller
Penfield, NY

John and Joan Oliphant
Victor, NY

A memorial fund has been established in the name of

Mr. Michael Arlen

Donations have been made in Mr. Arlen's memory by:

Richard and Carolyn Theobald
Levittown, PA

Robert Simpson
Morrisville, PA

Stephen and Catherine Sinak
Levittown, PA

Carole Snyder
Langhorne, PA

Lynn Harper
Langhorne, PA

A memorial fund has been established in the name of

Mrs. Dorothy Bayer

Donations have been made in Mrs. Bayer's memory by:

Herbert Bayer, *Plainfield, IL*

continued on page 14

A memorial fund has been established in the name of

Mrs. Frances Bena

Donations have been made in Mrs. Bena's memory by:

Bishop David Bena and Mary Ellen Bena, *Glenville, NY*

A memorial fund has been established in the name of

Mr. Bernard C. Colquett

Donations have been made in Mr. Colquett's memory by:

First Presbyterian Church Day School Faculty, *Jackson, MS*

A memorial fund has been established in the name of

Mr. Joseph Contrino

Donations have been made in Mr. Contrino's memory by:

Michael and Elizabeth Tricano, *North Babylon, NY*

A memorial fund has been established in the name of

Mr. Robert Copeland

Donations have been made in Mr. Copeland's memory by:

Joseph and Harriet Fenslage, *Wentzville, MO*

A memorial fund has been established in the name of

Ms. Carol Cordray

Donations have been made in Ms. Cordray's memory by:

Bass Pro, Inc., *Springfield, MO*

A memorial fund has been established in the name of

Mr. David Dunham

Donations have been made in Mr. Dunham's memory by:

Michael and Janine Dyer, *Eagle, MI*

A memorial fund has been established in the name of

Mrs. Gertrude Farney

Donations have been made in Mrs. Farney's memory by:

Deerfield High School
Deerfield, IL

Mark Moore
Schaumburg, IL

Candice Sagliano
Schaumburg, IL

A memorial fund has been established in the name of

Mrs. Jean Follrath

Donations have been made in Mrs. Follrath's memory by:

Michael and Loryn Follrath, *Minnetonka, MN*

A memorial fund has been established in the name of

Mrs. Erma Hollingshead

Donations have been made in Mrs. Hollingshead's memory by

John D. Woodfin
Vallejo, CA

Massone Mechanical, Inc.
Alamo, CA

Lisa Woodfin
Vallejo, CA

A memorial fund has been established in the name of

Ms. Betty Jones

Donations have been made in Ms. Jones' memory by:

Sylvia Brugger
Sewell, NJ

Evald and Barbara Eskilson
Barnegat, NJ

Jeffrey and Erica Shernoff
Cherry Hill, NJ

A memorial fund has been established in the name of

Mr. Joseph Kotelnicki

Donations have been made in Mr. Kotelnicki's memory by:

Dolores J. Kotelnicki
Indiana, PA

Joan Freda
Indiana, PA

Michael and Tammy Kotelnicki
Vienna, VA

Michael and Karen Kelley
McMurray, PA

Jim and Pat James
Zionsville, NJ

Poja and Patty Mehalko
Twin Rocks, PA

Gloria DeFabo
Indiana, PA

Douglas and Gloria Wilner
Indiana, PA

Brian and Martina Hughes
Indiana, PA

Todd Krug
Merion Station, PA

John and Jane Perdeus
Indiana, PA

David and Joan Aaron
Gaithersburg, MD

Clifford and Julie Geary
Indiana, PA

Kimberlee Cunkelman
Blairsville, PA

Jim and Nancy Miller
Indiana, PA

Todd and Lonie Brice
Indiana, PA

Lisa Travis
Fairfax, VA

Rebecca Snyder
Indiana, PA

Charles and Maryann Shoup
Blairsville, PA

James and Elaine Myers
Indiana, PA

Dennis Gehly Social Committee
Indiana, PA

Joseph and Dawn Wagner
Timonium, MD

Samuel and Heather Zaffuta
New Kensington, PA

George and Janet Wiley
Indiana, PA

Jenifer Reece
Fairfax, VA

Sharon Kash
Annandale, VA

Deborah A. Davenportt
Falls Church, VA

A memorial fund has been established in the name of

Mrs. Nancy Tash Manlove

Donations have been made in Mrs. Manlove's memory by:

Eleanor Frew, *Flossmoor, IL*

A memorial fund has been established in the name of

Mr. Richard Martinelli

Donations have been made in Mr. Martinelli's memory by:

Alfred and Marsha Luce
Rockville, MD

Edith Parnum
Wayne, PA

Edward and Morgia Polatsek
Marlton, NJ

A memorial fund has been established in the name of

Mr. Victor McFadden

Donations have been made in Mr. McFadden's memory by:

Maureen McFadden-Dorgan
Granger, IN

Thomas and Patty Troeger
South Bend, IN

Michael and Mary Sifferlen
Cumberland, IN

Daniel and Joan Mead
Grand Rapids, MI

Robert and Sarah Walz
Grosse lle, MI

Robert and Janice Sluka
Spring Lake, MI

Dan and Marianne Martin
Granger, IN

Terence and Laurie McFadden
South Bend, IN

Steve and Maryann McTigue
Mishawaka, IN

Harry and Joyce Kevorkian
Granger, IN

Shirley Roemer
South Bend, IN

John and Rhonda Nolan
South Bend, IN

Gregory and Shirley Labis
South Bend, IN

Gordon and Robin Slutsky
Granger, IN

Robert and Audrey Spaargaren
Granger, IN

Ronald and Barbara Mistretta
Grand Haven, MI

Robert E. Manning
Peoria, IL

KMZ Rosenman
Chicago, IL

Nicholas and Jacqueline Eufemi
South Bend, IN

Duthler Automotive Group
Kentwood, MI

Joseph and Victoria Dundon
South Bend, IN

Julie Martin
Indianapolis, IN

Mr. Victor McFadden *(continued)*

Kenneth and Barbara Fedder
Granger, IL

Thomas and Joan Bolka
Herndon, VA

William and Suzanne Johnson
La Grange, IL

Frank N. Magid Associates, Inc.
Marion, IA

Megan Hardiman
Chicago, IL

Thomas and Elaine Rath
Hinsdale, IL

Dale and Tina Freeman
Mishawaka, IN

Steve Nani
South Bend, IN

Don and Margaret Creed
South Bend, IN

Joseph and Shirley Hennessy
South Bend, IN

Barbara Bambenek
South Bend, IN

WNDU Michiana Telecasting Corp
South Bend, IN

Karen Nelund
South Bend, IN

J.J.A. Enterprises, Inc.
Mishawaka, IN

Anne McGraw
South Bend, IN

John Belting
South Bend, IN

Mary Stoeckinger
South Bend, IN

Eleanor Fails
South Bend, IN

Michael and Heidi Gaffney
West Roxbury, MA

William and Lois Mieras
Spring Lake, MI

Theodore Fox
Brighton, MI

Andrew Sylling
Stafford, VA

Sherril Mirkin
Mishawaka, IN

Harriet Kovatch
South Bend, IN

Richard Bonewitz
South Bend, IN

Glen and Virginia Smith
High Ridge, MO

Jacqueline Badics
Granger, IN

Vera Monahan
South Bend, IN

Jerry and Margaret Marley
South Bend, IN

Matthew and Catherine Koscielski
South Bend, IN

Jeffrey Kimmell
South Bend, IN

Sweeney Pfeifer Morgan & Stesiak
South Bend, IN

Eugene and Frances Kovacs
South Bend, IN

Kazimir and Dorothy Odrcic
South Bend, IN

Thomas and Kathleen Dennin
South Bend, IN

John and Helen Iams
South Bend, IN

John Dragovich
South Bend, IN

Ruby Stratigos
South Bend, IN

Michael Belting
South Bend, IN

Anne Loebach
South Bend, IN

Warren and Linda Verteramo
South Bend, IN

Ruth DesLauriers
Mishawaka, IN

Robert and Michelle O'Malley
South Bend, IN

Tom and Trudy Puleo
Grand Haven, MI

F. Gerard Feeney
South Bend, IN

James Gilroy
South Bend, IN

Roberto Parisi
South Bend, IN

The Croft Family
South Bend, IN

Fred and Julie Hollett
Plymouth, IN

Mary Simko
South Bend, IN

Frank and Mary Lyonnais
Stanwood, MI

Brian and Diane Healy
Granger, IN

Jack Zimmerman
South Bend, IN

The Valdiserri Family
Wilmette, IL

Mary and LeeAnn Rappelli
South Bend, IN

Josephine Bamber
Granger, IN

Richard and Mary Mitchell-Dick
Indianapolis, IN

Portage Township Trustee's Office
South Bend, IN

Joyce O'Connor
Winston Salem, NC

Rocco and Julia Ameduri
South Bend, IN

Richard and Sally Hendricks
South Bend, IN

Brad and Mary Lynne
Big Rapids, MI

Bob and Pat Skudlarek
South Bend, IN

Tom and Virginia Hart
Trenton, MI

Jack and Pat Hill
Grand Rapids, MI

Dan and Mary Ann Rogers
South Bend, IN

Jim and Teresa Stavros
South Bend, IN

Mike and Cindy Hoffman
Granger, IN

Larry and Jennifer Hart
Lansing, MI

MDS

Membership Information

The MDS Foundation would like to have you as a member. Membership is US$35 a year for physicians and other professionals. Patients, their families, and others interested in MDS may join at the reduced rate of $20. Membership benefits include quarterly issues of the *MDS News*, a special subscription rate of $109 for *Leukemia Research* (a substantial discount from the current subscription rate of $1,193), and the worldwide Centers of Excellence patient referral service.

If you would like additional information, please contact us at:

The MDS Foundation
36 Front Street, P.O. Box 353
Crosswicks, NJ 08515

Phone: 1-800-MDS-0839
Fax: 609-298-0590
Outside the US only: 609-298-1035

A memorial fund has been established in the name of

Mrs. Roberta McIntyre

Donations have been made in Mrs. McIntyre's memory by:

Parda Federal Credit Union
Ann Arbor, MI

David Weir
Bloomfield, MI

Nancy Lang
Troy, MI

David and Judith Smith
Ann Arbor, MI

David and Frances Pribish
Stamford, CT

David and Amy Whitton
Saline, MI

Carl and Anne Zilke
Clayton, MI

Derek and Kristen Deland
Tecumseh, MI

Karen Freeman and John Silber
Fullerton, CA

Lorraine McGillivray
Shelby Township, MI

Mary Lou McGillivray
Brook Park, OH

Paul and Barbara McGillivray
Macomb, MI

James and Kim Smoots
Macomb, MI

John and Alba Blaine
Lapeer, MI

Timothy and Diane Merritt
Brooklyn, MI

Richard and Cynthia Bousley
Dexter, MI

Terry and Ellen Landoski
Belleville, MI

George R. Flees
Mt. Clemens, MI

Dennis and Gail Babel
Grosse Pointe Woods, MI

Thomas and Jeanette Meyer
Tecumseh, MI

Harry and Mary Ann Boyd
Cincinnati, OH

Douglas and Brenda Schedeler
Brooklyn, MI

James and Michelle Peabody
Grosse Pointe, MI

Gregory Peter
Chelsea, MI

John and Marlene Kotcher
St. Clair Shores, MI

Carolyn Welsch
Grosse Pointe Woods, MI

Arthur and Mae Lang
Shelby Township, MI

Susan Golicic
Eugene, OR

A memorial fund has been established in the name of

Mr. Tracey Moore

Donations have been made in Mr. Moore's memory by:

Pat Rousculp
Springfield, OH

Barbara Heckert
Springfield, OH

Eugene and Betty Deel
Springfield, OH

continued on page 16

In Memorium (continued from page 15)

A memorial fund has been established in the name of

Mr. Thomas O'Mealy

Donations have been made in Mr. O'Mealy's memory by:

Sherry O'Mealy, *Montoursville, PA*

A memorial fund has been established in the name of

Mr. Alphonso Perona

Donations have been made in Mr. Perona's memory by:

Tony and Katy Haldezos
Milbrae, CA

W.D. and Ann Brooks
Fair Oaks, CA

William and Joan Willett
Orangevale, CA

George and Olga Canney
Bend, OR

Stephen and Sharon Borcich
Scottsdale, AZ

A memorial fund has been established in the name of

Dr. Alan James Peterson

Donations have been made in Dr. Peterson's memory by:

Richard and Delores Lopez
Santa Paula, CA

Dr. John Broms
Ventura, CA

Jeff and Nancy Horton
Paso Robles, CA

Steven and Diana Breig
Fillmore, CA

Dr. and Mrs. Jack Erbeck
Ventura, CA

Saticoy Country Club
Somis, CA

Evan and Frances Slater
Ventura, CA

Bill Herrera
Fillmore, CA

Lou and Theresa Landis
Hermosa Beach, CA

Holly Lehmer
Frisco, TX

Thomas and Bridget Seyler
Agoura Hills, CA

Marilyn Rafferty
Santa Paula, CA

Santa Paula Memorial Hospital Auxiliary
Santa Paula, CA

Gary and Carolyn Haeffelin
Bridgeport, NE

Eddy and Elaine Martinez
Santa Paula, CA

Roger and Patricia Peterson
Calabasas, CA

Eloise Tavares
Ventura, CA

Gary and Karin Gunther,
Oxnard Shores, CA

Douglas Dullenkopf
Santa Paula, CA

Mitch and Sheri Marvosh
Ventura, CA

Richard and Betty Hyde
Santa Paula, CA

Elbert and Anita Tate
Santa Paula, CA

Jack and Casey Dickensen
Santa Paula, CA

James and Susan Phelps
Palmdale, CA

Lucille Sparkman
Santa Paula, CA

The Medicine Shoppe
Ventura, CA

Leo Adair
Santa Paula, CA

John Shilton
Santa Paula, CA

Richard and Sally Cook
Santa Paula, CA

Ed Staben
Santa Paula, CA

John and Virginia Hardacre
Apple Valley, CA

Lola Law
Santa Paula, CA

Gordon Peterson
Longview, WA

Patricia Smoogen
Mammoth Lakes, CA

Virginia and Kimberly Seyler
Lancaster, CA

Richard Schmittou
Fillmore, CA

John Real
Ventura, CA

Russell and Elizabeth Hardison
Fillmore, CA

David and Susan Dollar
Fillmore, CA

Russell and Alissa Fox
C. Loretta Frank
Oxnard, CA

Philip and Georgia Peterson
Newbury Park, CA

Debbie Slater
Ventura, CA

Thomas and Yvonne Westervelt
Oxnard, CA

Roger Wunder
Santa Paula, CA

Harold and Donna Wunder
Santa Paula, CA

Harry and Dixie Bremer
Santa Paula, CA

A memorial fund has been established in the name of

Mr. Robert Pyle

Donations have been made in Mr. Pyle's memory by:

Marie Marty
St. Paul, MN

Duane and Margie Jacobs
Chaska, MN

Dr. J.G. Flint
Shoreview, MN

John and Melanie Gilberg
Maple Grove, MN

A memorial fund has been established in the name of

Mr. William Rudolph

Donations have been made in Mr. Rudolph's memory by:

Jerry and Paula Kelly, *Dunedin, FL*

A memorial fund has been established in the name of

Mr. Norman A. Sayer

Donations have been made in Mr. Sayer's memory by:

Donald Sayer, *Woodside, NY*

A memorial fund has been established in the name of

Mr. Frank Slomski

Donations have been made in Mr. Slomski's memory by:

Robert and Gretchen Bach
Erie, PA

James and Alison Samuels
Erie, PA

Frances Somolani
Erie, PA

Douglas Villella
Erie, PA

Irene Mielnik
Erie, PA

Thomas and Mary Ann Lubiejewski
Erie, PA

Joy Sweeting
Erie, PA

Jeffrey and Janet Dilley
Erie, PA

William and Marcy Rose
Burlington, MA

Ralph and Susan Riehl
Erie, PA

Edward and Linda Ondovcik
Cranberry Twp., PA

Dr. Warren Merguerian
Toms River, NJ

Prints & More by Holly
Erie, PA

Mark and Joni Vatavuk
Erie, PA

Caroline M. Staab
Erie, PA

A memorial fund has been established in the name of

Mr. Thomas Squier

Donations have been made in Mr. Squier's memory by:

Beverly Bash
Chico, CA

Robert and Evelyn Squier
Portal, AZ

Sigma Phi Gamma Delta Nu Chapter
Chico, CA

Reverend Kevin and Jennifer Gooding
South Bend, IN

Thelma Warren
Chico, CA

Joan Skwiercz
South Bend, IN

James and Alvina Walker
Grand Blanc, MI

Kjell and Barbara Berstrom
Chico, CA

Stephen Fidler
Goshen, IN

L.L. Geans Construction Co.
Mishawaka, IN

Jay and Cynthia Price
Carmel, IN

Laurie Quay
Carmel, IN

Mike Ackerman
Carmel, IN

Chris Ogg
Carmel, IN

Jeff Sheets
Carmel, IN

Bob Schmid
Carmel, IN

Jim Metken
Carmel, IN

Randy Surette
Carmel, IN

A memorial fund has been established in the name of

Mr. Albert J. Strohm

Donations have been made in Mr. Strohm's memory by:

Charles Strohm and Alice Wonsowski, *Downers Grove, IL*

International Clinical Trials: An Update

The following trials are current as of the date of this newsletter. We will update the list in The MDS News each quarter. If you are a treating physician who would benefit from any such study, you may want to contact the appropriate institution. If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

Clinical trials study new interventions (drugs or procedures) to evaluate their safety and effectiveness in humans. Trials follow a careful set of steps, allowing for the systematic gathering of information to answer questions and confirm hypotheses that were formed earlier, in either laboratory experiments or preliminary trials.

A clinical trial falls into one of four phases:

Phase I. This is the first time a drug is used in humans. The trial is designed to determine dosage, route of administration (oral, intravenous, or by injection), and schedule of administration (how many times a day or week). In this phase researchers also begin to determine the drug's safety. The phase I trial is normally conducted in healthy adults and enrolls only a small number of people.

Phase II. Patients with the disease receive the drug at dose levels determined in the earlier phase. The phase II trial begins to determine the effectiveness of the drug and provides more information about its safety.

Phase III. The drug is tested alone or against an approved standard drug. The typical phase III trial enrolls a large number of patients. If it is a comparison trial, patients may be randomly assigned to receive either the new drug or the standard intervention.

Phase IV. In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare.

Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

U.S. Trials

NATIONAL CANCER INSTITUTE TRIALS*

As we go to press the National Cancer Institute (NCI) has listed more than 100 clinical trials that focus on Myelodysplastic syndromes. Full study information on these trials is available at www.nci.nih.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.nci.nih.gov
- Click on "Finding Clinical Trials"
- on the next screen look for "Ways to Find Clinical Trials" and
- Click on "Search for Clinical Trials"
- Click on "Type of Cancer" and type in 'myelodysplastic syndromes'
- Hit search

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care. You can also contact 1-800-4-CANCER for more information.

ADVANCED CANCERS: A NEW TRANSPLANT METHOD

Researchers at the National Institutes of Health (NIH/DHHS) are investigating a new method of improving transplant results in individuals with advanced cancers. If you or someone you know are between the ages of 10 to 50 years old and have one of the following cancers: Myelodysplastic Syndrome, Leukemia, or Myeloproliferative Disorder, you may be able to participate in this clinical trial. To find out if you qualify, please call 1-800-411-1222 or visit www.cc.nih.gov.

Pharmion. AZA PH GL 2003 CL 001. A Survival Study in Patients with High Risk Myelodysplastic Syndromes Comparing Azacitidine versus Conventional Care. The purpose of this study is to determine whether patients with high-risk myelodysplastic syndromes (MDS) treated with azacitidine have improved survival compared to conventional care treatments. The study will also assess the effect of treatments on response, duration of response, and transformation to acute myeloid leukemia (AML).

Telik, Inc. Phase I-IIa trial to evaluate the safety and efficacy of TLK199 in patients with myelodysplastic syndrome (MDS). Eligible patients must have a diagnosis of MDS, be at least 18 years old and ineligible or refusing bone marrow transplant.

For more information, please go to www.clinicaltrials.gov.

Other U.S. Trials

Barbara Ann Karmanos Cancer Institute, Detroit, MI. D-696. Allogenic and syngenieic marrow transplantation in patients with acute non-lymphocytic leukemia. Contact: Jared Klein, MD. Phone: 313-963-2533.

Barbara Ann Karmanos Cancer Institute, Detroit, MI. POG A2971: Treatment Of Children with Down Syndrome and Acute Myeloid Leukemia, Myelodysplastic Syndrome, or Transient Myeloproliferative Disorder. Contact: Jeffrey Taub, MD. Phone: 313-963-2533.

Cancer Institute Medical Group, Los Angeles, CA. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Lawrence D. Piro, MD. Phone: 310-231-2182.

Case Western Reserve University, Cleveland, OH. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Donna Kane, RN. Phone: 216-844-8609.

Cedars-Sinai Medical Center, Los Angeles, CA. Phase II study to determine if an oral, relatively non-toxic, novel vitamin D3 compound, paricalcitol, (Zemplar) can improve red, white and platelet counts as well as decrease the risk of development of leukemia, without causing undue toxicity in patients with myelodysplastic syndromes (MDS). Patients will receive oral administration of paricalcitol in increasing doses. Contact: H. Phillip Koeffler, MD. Phone: 310-423-4609.

Children's Hospital of New York Presbyterian, New York, NY. 01-504. Phase II trial using fludarabine, busulfan, and anti-thymocyte globulin (ATG) to evaluate the efficacy of reduced intensity allogeneic stem cell transplantation to treat MDS. Eligible patients must have 1) MDS and <5% bone marrow myeloblasts at diagnosis; 2) minimum of >10% CD33 positivity; 3) adequate organ function (renal, hepatic, cardiac and pulmonary); 4) age <65 years; 5) matched family donor (5/6 or 6/6),unrelated donor (5/6 or 6/6), or cord blood donor (3/6, 4/6, 5/6, 6/6). Contact: Mitchel S. Cairo, MD. Phone: 212-305-8316.

Cleveland Clinic Foundation, Cleveland, OH. IRB5777. Phase II, multicenter, open-label study of the safety and efficacy of high-dose pulse administration DN-101 (calcitrol) in patients with myelodysplastic syndrome. Contact: Liz Kuczkowski. Phone: 216-445-3795.

Duke University Medical Center, Durham, NC. Phase II trial to assess the value of non-myeloablative allogeneic therapy (mini bone marrow transplant) for patients with aplastic anemia or myelodysplastic syndromes. Patients must have severe disease to be eligible and may have either a matched sibling, mismatched family member, or large cord blood unit found for use on our trial. Contact: David A. Rizzieri, MD at Rizzi003@mc.duke.edu.

Fallon Clinic. Worcester, MA. PR01-09-010. Phase II study on the effectiveness of low dose Thalidomide combined with Erythropoietin in the treatment of anemia in patients with low and intermediate risk-1 myelodysplastic syndromes. Contact: Laszlo Leb, MD. Phone: 508-368-3168.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1297. Radiolabeled BC8 (anti-CD-45) Antibody Combined with Cyclophosphamide and Total Body Irradiation Followed by HLA-Matched Related or Unrelated Stem Cell Transplantation as Treatment for Advanced Acute Myeloid Leukemia and Myelodysplastic Syndrome. Phase II trial to determine the efficacy (as measured by survival and disease-free survival) and toxicity of a regimen of cyclophosphamide, TBI, plus the maximum tolerated dose of I labeled BC8 (anti-CD45) antibody in patients with AML beyond first remission receiving HLA matched related hematopoietic stem cell transplants. Contact: J. Pagel, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1432. Phase I trial to determine the maximum tolerated dose of radiation delivered via BC8 antibody when combined with the non-myeloablative regimen of fludarabine, TBI + CSP/MMF in elderly patients (>50 and <70 years) with advanced AML or high risk MDS. Contact: J. Pagel, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1591. Phase I trial to determine whether stable allogeneic engraftment from related and unrelated HLA-mismatched stem cell donors can be safely established using a non-myeloablative conditioning regimen plus escalating doses of the anti-CD52mAb Campath® in patients with hematologic malignancies. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1732. Phase II trial to evaluate the efficacy of non-myeloablative allogeneic HCT from related and unrelated donors for the treatment of patients with MDS and MPD, who are not candidates for conventional allogeneic HCTG due to advanced age or serious comorbid conditions. Contact: B. Sandmaier, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1813. Phase III trial to compare the non-relapse mortality at 1-year after conditioning with TBI alone vs. fludarabine/TBI in heavily pretreated patients with hematologic malignancies at low/moderate risk for graft rejection who have HLA-matched related donors. Contact: B. Sandmaier, MD. Phone: 206- 288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1536. Transplantation of peripheral blood stem cells from related or unrelated volunteer donors in patients with "less advanced" MDS. Conditioning therapy includes busulfan (targeted to a pre-determined plasma level) and cytoxan (targeted BUCY); patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1596. Transplantation from related donors for high-risk patients with MDS. Conditioning includes a "non-myeloblative" regimen of fludarabine and 200 cGy of total body irradiation. Patients are evaluated individually for eligibility. Contact: David Maloney, MD, PhD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1478. Non-transplant therapy for "less advanced" MDS with ATG plus Enbrel. No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-667-4324.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #117. Transplantation of patients with aplastic anemia from related donors following conditioning with antithymocyte globulin (ATG) and cytoxan (CY). Patients up to 55 years of age. Contact: R. Storb, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #800. Transplantation from unrelated donors for patients with aplastic anemia who have failed immunosuppressive therapy. Conditioning involves ATG, CY and 200 cGy of total body irradiation. Patients up to 55 years of age. Contact: H.J. Deeg, MD. Phone 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1641. Transplantation from unrelated donors for high-risk patients with MDS. Conditioning will be with a "non-myeloablative" approach using 200 cGy of TB1 and fludarabine. No age restriction (other exclusion criteria exist). Contact: M. Maris, MD. Phone 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1723. Transplantation from related or unreleased donors for patients with advanced MDS or myeloproliferative disorders. Conditioning includes busulfan (targeted to a predetermined plasma level) and Cytoxan (targeted BUCY) with the addition of thymoglobulin; patients up to 65 years of age. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1781. Non-transplant therapy for "less advanced" transfusion-dependent MDS with DN-101 (Calcitriol). No age restrictions. Contact: H.J. Deeg, MD. Phone: 206-288-1024.

Froedtert Memorial Lutheran Hospital, Milwaukee, WI. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: David Vesole, MD. Phone: 414-805-4629.

Georgetown University, Washington, DC. Clinical and biologic effects of arsenic trioxide in MDS. Contact: B. Mavromatis, MD. Phone: 202-784-0124.

Indiana University Medical Center, Indianapolis, IN. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Larry Cripe, MD. Phone: 317-274-0901.

Johns Hopkins Oncology Center, Baltimore, MD. J0136. Vaccination in peripheral stem cell transplant setting for acute myelogenous leukemia: The use of autologous tumor cells with an allogeneic GM-CSF producing bystander cell line. Contact: Julie Yerian. Phone: 410-614-1766.

Johns Hopkins Oncology Center, Baltimore, MD. J0255. Phase II study of the farnesyl transferase inhibitor Zarnestra in previously untreated poor-risk acute myeloid leukemia and myelodysplastic syndromes. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J0051. Dose finding study of bryostatin-1 and GM-CSF for resistant myeloid malignancies. Contact: Julie Yerian. Phone: 410-614-1766.

Johns Hopkins Oncology Center, Baltimore, MD. J9950. Phase I dose de-escalation to minimal effective pharmacologic dose trial of sodium phenylbutyrate in combination with 5-azacytidine in patients with myelodysplastic syndromes. Contact: Tianna Dauses. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J9879. Phase I, dose-finding trial of sodium phenylbutyrate in combination with all trans-retinoic acid (ATRA) in patients with myelodysplastic syndromes and acute myeloid leukemia. Contact: Karen Friel. Phone: 410-502-7114.

Johns Hopkins Oncology Center, Baltimore, MD. J0253. Phase I clinical-laboratory study of the histone deacetylase (HDA) Inhibitor MS-275 in adults with refractory and relapsed hematologic malignancies. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J0252. Phase II study of the farnesyl transferase inhibitor Zarnestra in complete remission following induction and/or consolidation chemotherapy in adults with poor-risk acute myelogenous leukemia (AML) and high-risk myelodysplasias. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J9852. Granulocyte macrophage-colony stimulating factor (GM-CSF) after T-lymphocyte-depleted allogeneic BMT for myelodysplastic syndromes. Contact: Tianna Dauses. Phone: 410-502-7110.

Los Angeles Hematology and Oncology Assoc., Los Angeles, CA. Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: C. Gota, MD. Phone: 818-409-0105.

MD Anderson Cancer Center, Houston, TX. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Stefan Faderl, MD. Phone: 713-563-1688.

MD Anderson Cancer Center, Houston, TX. Open-Label, Phase II Study to Evaluate the Efficiency and Safety of the Farnesyltransferase Inhibitor Zarnestra (R115777) in Subjects with High-Risk Myelodysplastic Syndrome (MDS). Contact: Razelle Kurzrock, MD.

MD Anderson Cancer Center, Houston, TX. ID02-266. Therapy of inversion (16) and T (8:21) AML/MDS with fludarabine and Ara-C. Contact Elihu H. Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center, Houston, TX. Phase I/II Study of PR1 (NSC698102) Human Leukemia Peptide Vaccine with Incomplete Freund's Adjuvant (NSC 675756). Contact: Jeffrey Molldrem, MD. Phone: 713-745-4820.

MD Anderson Cancer Center, Houston, TX. Phase II Open-Label Study of the Intravenous Administration of Homoharringtonine (CGX-635) in the Treatment of Myelodysplastic Syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Arsenic Trioxide in the Treatment of Myelodysplastic Syndromes. Contact: Miloslav Beran, MD. Phone: 713-792-2248.

MD Anderson Cancer Center, Houston, TX. Phase II, Multicenter, Open-Label Study of the Safety and Efficacy of High-Dose Pulse Administration DN-101 (Calcitriol) in Patients with Myelodysplastic Syndrome. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

MD Anderson Cancer Center, Houston, TX. Randomized, Open-Label, Phase III Trial of Decitabine (5-AZA-2'Deoxycytidine) Versus Supportive Care In Adults with Advanced-Stage Myelodysplastic Syndrome. Contact: Jean-Pierre Issa, MD. Phone: 713-745-2260.

MD Anderson Cancer Center, Houston, TX. Safety and Efficacy Trial of Bevacizumab: Anti-VEGF Humanized Monoclonal Antibody (NSD 704865) Therapy for Myelodysplastic Syndrome (MDS). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Neumega (Oprelvekin)(Interleukin-11) in Patients with Myelodysplastic Syndrome. Contact: Razelle Kurzrock, MD. Phone: 713-794-1226.

MD Anderson Cancer Center, Houston, TX. Multicenter Phase I/II Study of Continuous Oral Administration of SCH 66336 in Patients with Advanced Myelodysplastic Syndrome, Acute Myelogenous Leukemia, Chronic Myelogenous Leukemia in Blast Crisis, Acute Lymphoblastic Leukemia. Contact: Jorge Cortes MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Phase II Study of Intravenous Homoharringtonine in Chronic Myelogenous Leukemia (CML). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. Therapy of Hypereosinophilic Syndrome, Polycythemia Vera, Atypical CML or CMML with PDGF-R Fusion Genes, or Mastocytosis with Gleevec (STI571). Contact: Jorge Cortes, MD. Phone: 713-794-5783.

MD Anderson Cancer Center, Houston, TX. DCTER Chemotherapy in Patients Ages 1 through 49 with Untreated AML or High-Risk Myelodysplasia. Contact: Elihu Estey, MD. Phone: 713-792-7544.

MD Anderson Cancer Center, Houston, TX. Phase II study of clofarabine in combination with cytarabine (Ara-C) in pts ≥50 yrs with newly diagnosed and previously untreated acute myeloid leukemia (AML) and high-risk myelodysplastic syndrome (MDS) (≥10% bone marrow blasts). Contact: Stefan Faderl, MD. Phone: 713-745-4613.

MD Anderson Cancer Center, Houston, TX. DM02-203. Phase Ia, Open-Label, 3-Arm, Dose Escalation Study of PTK787/ZK 222584. Contact: Francis Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center, Houston, TX. ID03-0044. Phase I Clinical Trial of Oral Suberoylanilide Hydroxamic Acid (SAHA) in Patients with Advanced Leukemias. Contact: Guillermo Garcia-Manero, MD. Phone: 713-745-3428.

MD Anderson Cancer Center, Houston, TX. DM01-646. Phase I Study of ABT-751 in Patients With Refractory Hematologic Malignancies. Contact: Francis Giles, MD. Phone: 713-792-8217.

MD Anderson Cancer Center, Houston, TX. Phase II trial using ATG and Fludarabine or Cyclosporine to evaluate the efficacy of immunosuppression to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have RA or RARS and low blood counts. Contact: Jeffrey Molldrem, MD. Phone: 713-745-4820.

MD Anderson Cancer Center, Houston, TX. ID99-059. Phase II trial using ATG/CSA; ATG/Fludarabine. Eligible patients must have MDS of subtype RA, blasts <5% in bone marrow that require > unit of PRBC/month for >2 months, platelet count <50,000/m^3, or neutrophil count <500/m^3, IPSS score >2. Contact: Jeffery Molldrem, MD. Phone: 713-745-4820.

Memorial Sloan-Kettering Cancer Center, New York, NY. 99-057. Phase I study of salicylate for adult patients with advanced myelodysplastic disorders, acute myelogenous leukemia or chronic lymphocytic leukemia. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Memorial Sloan-Kettering Cancer Center, New York, NY. 00-116. Pilot study of FR901228 or Depsipeptide (NSC#630176) for adult patients with advanced hematologic disorders. Contact: Virginia Klimek, MD. Phone: 212-639-6519.

Memorial Sloan-Kettering Cancer Center, New York, NY. 02-063. Tolerability and PK/PD of multiple oral doses of CT53518 in patients with acute myelogenous leukemia. Contact: Mark Heaney, MD, PhD. Phone: 212-639-2275.

Mount Sinai Medical Center, New York, NY. Phase I-II Pilot Study of Divalproex Sodium and All-Trans-Retinoic Acid (ATRA) in Relapsed or Refractory Acute Myeloid Leukemia (except M3, FAB Classification). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

Mount Sinai Medical Center, New York, NY. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Lewis Silverman, MD. Phone: 212-241-5520.

National Heart, Lung, and Blood Institute, Bethesda, MD. 04-H-0026. Randomized Trial of Daclizumab versus ATG for Myelodysplastic Syndrome. Clinical trial comparing the effectiveness of treatment with either a new immunosuppressive drug (Daclizumab) or antithymocyte globulin (ATG) for patients with myelodysplastic syndrome. The study may help increase blood counts, reduce anemia symptoms, and/or reduce dependence on immunosuppressive medications and transfusions. If you are determined to be eligible to participate and you agree to join, it will be determined by chance whether you receive either daclizumab or ATG. If the treatment you are assigned does not work, you may subsequently receive the other treatment. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 01-H-0162. Stem Cell Transplantation for Older Patients with Myelodysplastic Syndrome. If you are 55 to 75 years of age and have been diagnosed with MDS, you may be eligible for a transplant procedure designed to decrease a major transplant complication, graft-versus-host disease (GVHD). Under evaluation is a novel method of treating your donor's cells prior to transplant. You must have an HLA-matched brother or sister to participate. We will do the blood testing free of charge to see if your sibling is a match upon request. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 03-H-0192. Stem Cell Transplantation and T-Cell Add Back to Treat Myelodysplastic Syndromes. Clinical trial designed to decrease graft versus host disease, promote engraftment, and improve immune system recovery following a bone marrow stem cell transplant. You must have an HLA matched brother or sister donor to participate in this trial. Contact: Laura Wisch. Phone: 301-402-0797.

National Heart, Lung, and Blood Institute, Bethesda, MD. 03-H-0209. Stem Cell Transplant for MDS from a partially HLA-matched family member. Many patients are not considered for a stem cell transplant because an HLA-matched sibling or unrelated donor is unavailable. For such patients, the only curative option is a transplant from a partially HLA-matched family member. If you are 10-50 years of age and have been diagnosed with advanced myelodysplastic syndrome, you may be eligible for a clinical trial of a transplant procedure that evaluates using peripheral blood stem cells from an HLA-mismatched family donor. Eligible patients are not asked to pay for their medical treatment and hospital costs. Contact: Laura Wisch. Phone: 301-402-0797.

Oregon Health & Science University, Portland, OR. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 7002. Tolerability and PK/PD of Multiple Oral Doses of CT53518 in Patients with Acute Myelogenous Leukemia. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 7597. Phase II, Multicenter, Open Label Study of the Safety and Efficacy of High-dose Pulse Administration DN-101 (Calcitriol) in Patients with Myelodysplastic Syndrome. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 7377. Randomized, Multi-Center, Double-Blind, Placebo-Controlled Trial Assessing the Safety and Efficacy of Thalidomide (Thalomid®) for the Treatment of Anemia in Red Blood Cell Transfusion-Dependent Patients with Myelodysplastic Syndromes. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 7039. Randomized Controlled Trial of Posaconazole (SCH56592) vs. Standard Azole Therapy for the Prevention of Invasive Fungal Infections Among High-Risk Neutropenic Patients. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 4252. Transplantation of Unrelated Donor Marrow or Placental Blood Hematopoietic Stem Cells for the Treatment of Hematological Malignancies. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 6756. Low-Dose TBI and Fludarabine Followed by Nonmyeloablative Unrelated Donor Peripheral Blood Stem Cell Transplantation Using Enhanced Postgrafting Immunosuppression for Patients with Hematologic Malignancies and Renal Cell Carcinoma – A Multi-Center Trial. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 6684. Nonmyeloablative PBSC Allografting from HLA Matched Related Donors Using Fludarabine and Low Dose TBI with Disease-Risk Based Immunosuppression. FHCRC Protocol #1596.00. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 6370. Low Dose Total Body Irradiation and Fludarabine Followed by HLA Matched Allogeneic Stem Cell Transplantation for Hematologic Malignancies– A Multi-Center Study. Contact: Peter Curtin, MD. Phone: 503-494-5064.

Oregon Health & Science University, Portland, OR. 6615. Non-Myeloablative Allogeneic Hematopoietic Cell Transplantation for the Treatment of Myelodysplastic Syndromes and Myeloproliferative Disorders (Except CML). Contact: Peter Curtin, MD. Phone: 503-494-5064.

Roswell Park Cancer Institute, Buffalo, NY. PTK787. Phase II study of an oral VEGF agent in myelodysplastic syndromes. Contact: Maria Baer, MD. Phone: 716-845-8840.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 99-14. Pilot study of Thalidomide (Thalidomid) combined with Pentoxyfilline, Ciprofloxacin and Dexamethasone (PCD) in patients with myelodysplastic syndromes. This is a Phase II trial using anticytokine and antiangiogenic therapy to evaluate the efficacy of Thalidomide (Thalomid) to treat MDS. Eligible patients must have MDS (RA, RARS or RAEB). Addendum: Reduced dose of Pentoxyfilline (400mg po TID), No Cipro, No Decadron. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 801-001. Multicenter, open-label, dose-escalation study to determine the safety and preliminary efficacy of CC-1088 in treatment of myelodysplastic syndromes. Eligible patients must have RA or RARS. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-04. Phase IIB study using Thymoglobulin in transfusion dependent patients with myelodysplastic syndrome. Open to FAB types RA, RARS, RAEB. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-11. Pilot study to test the efficacy of infliximab (Remicade) in patients with low-risk myelodysplastic syndromes. Eligible patients must be transfusion dependent or hemoglobin < 9 grams, and an IPSS score < 1.5, and cannot have a history of clinically significant cardiac disease or CHF. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2001-12. Pilot study to determine the clinical effects of the proteasome inhibitor PS-341 in patients with myelodysplastic syndromes. All FAB types are eligible. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2001-13. Randomized, open-label, Phase III trial of Decitabine (5-Aza-2'-Deoxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndromes. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2002-02. Phase II trial to evaluate the efficacy of Trisenox in patients with MDS, followed by thalidomide in non-responders. Eligible patients must belong to IPSS int 1 or higher, have adequate hepatic and renal function as defined by specific laboratory parameters, and have an ECOG PS of 0-2. Patients will receive Trisenox alone for six months. Patients who do not respond will have thalidomide added to the regimen at 6 months. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Stanford University Medical Center, Stanford, CA. CTEP #2771. Safety and efficacy of bevacizumab: humanized monoclonal anti-VEGF antibody therapy for myelodysplastic syndrome. Contact: Peter Greenberg, MD or Kathy Dugan, RN. Phone: 650-723-8594.

Stanford University, Stanford, CA. Study of DARBEPOETIN ALFA in Patients with MDS. Primary objectives are 1) to assess erythroid response to DARBEPOETIN ALFA, as determined by changes in hemoglobin and /or red blood cell (RBC) transfusion-dependence. 2) to describe the safety profile of DARBEPOEITN ALFA in patients with MDS. Contact: Sylvia Quesada, R.N. Phone: 650-725-4041.

Stanford University, Stanford, CA. Bevacizumab in Treating Patients With Myelodysplastic Syndrome. Multi-center trial with participating centers in Arizona, California, Texas. Contact: Sylvia Quesada, R.N. Phone: 650-725-4041.

St. Jude Children's Research Hospital, Memphis, TN. DSAML. Treatment of children with down syndrome (DS) and acute myeloid leukemia (AML), myelodysplastic syndrome (MDS), and transient myeloproliferative disorder (TMD). Contact: Nobuko Hijiya, MD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. AML02. Collaborative trial for the treatment of patients with newly diagnosed acute myeloid leukemia or myelodysplasia. Contact: Jeffrey Rubnitz, MD, PhD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. HAPSCT. Phase III randomized trial to evaluate haploidentical stem cell transplantation utilizing purified CD34+ hematopoietic cells for patients with hematologic malignancies: a randomized study comparing positive and negative selection methodologies. Contact: Gregory Hale, MD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. MUDSCT. Phase III controlled trial to evaluate hematopoietic stem cell transplantation for patients with hematologic malignancies: a comparison of T-cell depleted bone marrow with unmanipulated bone marrow. Contact: Edwin Horwitz, MD, PhD. Phone: 901-495-3300.

St. Jude Children's Research Hospital, Memphis, TN. REFSCT. Pilot study to evaluate haploidentical stem cell transplantation utilizing T-Cell depletion as therapy for patients with refractory hematological malignancies. Contact: Ely Benaim, MD. Phone: 901-495-3300.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. D-0007. Randomized, open-label, Phase III trial of decitabine (5-aza-2'-deoxycytidine) versus supportive care in adults with advanced-stage myelodysplastic syndrome. This Phase III trial evaluates the efficacy of decitabine to treat MDS. Eligible patients may have de novo or secondary MDS. Growth factors (G-CSF, erythropoietin), steroids, hormones or chemotherapy for treatment of MDS are not allowed for 2 weeks prior to enrollment. Contact: Craig Rosenfeld, MD. Phone: 972-566-7790.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. SMC-101-1020. Open-label, prospective, stratified, randomized, controlled, multicenter, Phase IIB study of the impact of Thymoglobulin therapy on transfusion needs of patients with early myelodysplastic syndrome. This protocol evaluates Thymoglobulin therapy for 4 days. Eligibility includes low risk MDS (RA, RAEB<10%), IPSS <1.0, transfusion dependence, no prior chemotherapy allowed. Contact: Craig Rosenfeld, MD. Phone: 972-566-7790.

Texas Oncology Medical City Dallas Hospital, Dallas, TX. T-MDS-001. Multicenter, randomized, double-blind, placebo-controlled trial comparing best supportive care and thalidomide for the treatment of anemia in patients with myelodysplastic syndrome followed by an open-label treatment with thalidomide. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. Contact: Craig Rosenfeld, MD. Phone: 972-566-7790.

University of Alabama at Birmingham Comprehensive Cancer Center, Birmingham, AL. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Peter Emanuel, MD. Phone: 205-975-2944.

University of Arizona Cancer Center, Tucson, AZ. HSC #02-11. Safety and efficacy trial of bevacizumab: anti-vegf humanized monoclonal antibody therapy for MDS. Contact: Daruka Mahedevan, MD. Phone: 520-626-2340.

University of California at Los Angeles (UCLA) Medical Center, Los Angeles, CA. Randomized, multicenter, double-blind, placebo controlled trial assessing the safety and efficacy of thalidomide (Thalidomid) for the treatment of anemia in patients with myelodysplastic syndromes. Recently, treatment with thalidomide has been reported to improve the anemia in some patients with MDS. The purpose of this study is to further evaluate the effect of thalidomide or placebo pills (50:50 chance) for 24 weeks. Thereafter, all subjects can receive thalidomide for an additional 24 weeks. The effect of treatment on transfusions and quality of life will be evaluated. The most common side effects of thalidomide include severe birth defects, drowsiness, weakness, rash, shortness of breath, fluid retention, constipation, low blood pressure, decreased white blood counts, slow heart beats and nerve damage. Contact: Ron Paquette, MD. Phone: 310- 825-5608.

University of Louisville, Louisville, KY. #541.02. Pilot study of arsenic trioxide and amifostine for the treatment of myelodysplastic syndromes. Eligible patients must have a confirmed diagnosis of MDS. For patients with lower-risk only: documented red blood cell dependence, defined as the inability to maintain a hematocrit of >25% without transfusion support and patients with serum erythropoietin less than 200 IU/mL at screening should have failed to respond to a trial of recombinant erythropoietin (EPO) administered in accordance with institutional guidelines. Patients must have an ECOG PS 0-2 and adequate hepatic and renal function as evidenced by specific laboratory criteria. Contact: R. Herzig, MD. Phone: 800-234-2689.

University of Pennsylvania Cancer Center, Philadelphia, PA. A pilot study of valproic acid in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

University of Pennsylvania Cancer Center, Philadelphia, PA. Pilot study of arsenic trioxide in patients with MDS. Contact: Selina Luger, MD. Phone: 215-662-6348.

University of Texas Health Science Center at San Antonio, San Antonio, TX. Phase I/IIa Study of TLK199 HCl Liposomes for injection in Myelodysplastic Syndromes. Contact: Natalie Callander, MD. Phone: 210-617-5300 Ext. 4720.

University of Texas, UT Health Science Center, San Antonio, TX. Randomized, double-blind, Phase II study of the matrix metalloproteases inhibitor Prinomastat in patients having myelodysplastic syndromes. Eligible patients must be over 18 years of age and have a diagnosis of MDS of at least 8 weeks duration, hemoglobin <9.0 g/dL (or be transfusion dependent) with adequate renal/hepatic function of serum creatinine less than or equal to 1.5 mg/dL and serum total bilirubin less than or equal to 2.0 mg/dL. Contact: Natalie Callander, MD. Phone: 210-567-4848.

University of Washington, Seattle, WA. UW-26-245-B. Phase I trial using subcutaneous, outpatient injection to evaluate the efficacy of Interleukin-2 to treat MDS. Eligible patients must have either refractory anemia, refractory anemia with ringed sideroblasts, refractory anemia with excess blasts, or chronic myelomonocytic leukemia; more than 30 days since any prior treatment for MDS; Karnofsky performance status >70; serum creatinine <2.0 mg/dL; bilirubin <1.6 mg/dL or SGOT <150. Contact: John A. Thompson, MD. Phone: 206-288-2015.

University of Wisconsin, Department of Medicine, Madison, WI. HO 02402. Phase I/II trial to evaluate the efficacy of Ontak (Denileukin Diftotox) for treating MDS. Participants must have no prior treatment with Ontak or ATG and must be at least 18 years old. Contact: Mark Jucket, MD. Phone: 608-263-1836.

University of Wisconsin, Department of Medicine, Madison, WI. HO 02403. Phase II trial using Doxercalciferol (Vitamin D) for treating MDS. Participants must have no prior exposure to doxercalciferol and must be at least 18 years old. Contact: Mark Jucket, MD. Phone: 608-263-1836.

Wake Forest University School of Medicine, Winston-Salem, NC. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndrome: Pilot trial where patients with low-risk MDS are treated with 2000 IU daily vitamin D3 for 6 months. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Washington University School of Medicine, St. Louis, MO. Multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Alisa Ruddell. Phone: 314-454-4095.

Western Pennsylvania Cancer Institute, Pittsburgh, PA. AZA PH GL 2003 CL 001. Multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Michelle Marietti, RN. Phone: 412-578-5346.

European Trials

AUSTRALIA

The Newcastle Mater Miseriecordiae Hospital, New South Wales. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Arno Enno. Phone: +61 2 4921 1215.

Princess Alexandra Hospital, Queensland. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Anthony Mills. Phone: +61 7 3240 2086.

Royal Adelaide Hospital, South Australia. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Noemi Horvath. Phone: +61 8 8222 3550.

The Alfred Hospital, Victoria. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Andrew Spencer. Phone: +61 3 9276 3392.

The Royal Perth Hospital, Western Australia. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Richard Herrman, MD. Phone: +61 8 9224 2405.

ENGLAND

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Multi-center study of the role of 5-Azacitidine in high risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Randomized study of GCSF + Epo versus supportive care in low risk MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

The Royal Bournemouth Hospital. Multi-centre study of the role of 5-Azacytidine in high risk MDS (beginning Spring 2004). Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

The Royal Bournemouth Hospital. Multi-centre trial of CEP-701 in older patients with AML. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

The Royal Bournemouth Hospital. Low dose antithymocyte globulin in elderly patients with MDS and aplastic anaemia. Contact: Sally Killick, MD. Phone: 44 (0) 11202 704783.

FRANCE

Institute Paoli Calmettes, Marseilles. Phase I/II multi-center study of arsenic trioxide in patients with MDS. Contact: Norbert Vey, MD. Phone: +33 4 91223695.

Institute Paoli Calmettes, Marseilles. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Norbert Vey, MD. Phone: +33 4 91223695.

Hopital Beaujon, Clichy. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Pierre Fenaux, MD. Phone: +33 1 40874522.

Chu Purpan, Toulouse. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Guy Laurent, MD. Phone: +33 5 61772078.

Chu De Nantes, Nantes. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Beatrice Mahe, MD. Phone: +33 2 40083252.

Che De Lille, Lille. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Bruno Quesnel, MD. Phone: +33 3 20446640.

Hopital Cochin, Paris. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Francois Dreyfus, MD. Phone: +33 1 58412120.

GERMANY

Heinrich-Heine University Dusseldorf. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

University Hospital Frankfort/Main. Antithymocyte Globulin (ATG) and Cyclosporine (CSA) to Treat Patients with Myelodysplastic Syndromes. A randomized trial comparing ATG+CSA with best supportive care Amended Protocol SAKK 33/99. Contact: Wolf-K. Hofmann, MD. Phone: +49-69-6301-4802.

University Hospital Frankfort/Main. Phase II Study with Thalidomide in patients with myelodysplastic syndromes. Contact: Wolf-K. Hofmann, MD. Phone: +49-69-6301-4802.

University Hospital Frankfort/Main. LAQ824 (inhibitor of histone-deacetylase) in patients with relapsed/refractory AML, advanced CLL, CML in blast crisis or advanced MDS. Contact: Wolf-K. Hofmann, MD. Phone: +49-69-6301-4802.

University Hospital Freiburg. Phase II study of low-dose intravenous decitabine in patients aged >60 years with acute myeloid leukemia who are not eligible for standard induction chemotherapy. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

University Hospital Freiburg. Intravenous low-dose decitabine versus supportive care in elderly patients with primary Myelodysplastic Syndrome (MDS) (>10% blasts or high-risk cytogenetics), secondary MDS or Chronic Myelomonocytic Leukemia (CMML) who are not eligible for intensive therapy: an EORTC-German MDS Study Group randomized Phase III study. Contact: Michael Lübbert, MD, PhD. Phone: +49-761-270-3279.

University Hospital Hamburg. Allogeneic stem cell transplantation after toxicity-reduced conditioning regimen with treosulfan and fludarabine for patients with MDS or sAML, who were not eligible for a standard conditioning regimen: a Phase II study. Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-4851.

University Hospital Hamburg. Dose-reduced versus standard conditioning followed by allogeneic stem cell transplantation in patients with MDS or sAML. A randomized Phase III study (will start in May 2004). Contact: Nicolaus Kröger, MD. Phone: +49-40-42803-4851.

HUNGARY

Semmelweis University School of Medicine, Budapest. Investigation of the multifactorial cause of iron overload by testing HFE gene mutations: C282Y and H63D, determination of copper and coeruloplasmin level, analysis of transferring receptor mutation and also TNF-alpha promoter gene polymorphism in MDS patients. Contact: Judit Varkonyi, MD, PhD. Phone/Fax: 361-355-8251.

ITALY

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase III clinical trial comparing a single, weekly dose of recombinant erythropoietin alpha (40.000 units) alone versus the combination of this treatment plus low-dose thalidomide for anemic, low-risk MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539. .

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase I/II clinical evaluating the effect of long-acting erythropoietin darboepoietin-alpha in low-risk, anemic MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

Unit of Hematology and Stem Cell Transplantation, IRCCS "Casa Sollievo della Sofferenza" Hospital. A Phase I/II clinical study on allogenic "conventional" and "mini" (non-myelosuppressive) peripheral blood stem cell transplantation in patients with high risk MDS. Contact: Dr. Pellegrino Musto. Phone: 39 (0) 882-410295-539.

POLAND

Jagiellonian University, Cracow. A randomized trial comparing Antithymocyte Globulin (ATG) and Cyclosporine (CSA) with best supportive care in patients with MDS. Contact: Prof. Aleksander B. Skotnicki, MD. Phone: +48-12-421-3693.

Jagiellonian University, Cracow. Phase I/II study of Thalidomide in low-risk MDS. Contact: Pawel Sledziowski, MD. Phone: +48-12-424-7600.

Jagiellonian University, Cracow. Phase III clinical trial of Amifostine/pentoxifylline/ciprofloxacin/dexamethasone for low-risk MDS. Contact: Janusz Krawczyk, MD. Phone: +48-12-424-7600.

Jagiellonian University, Cracow. Phase I/II study of Arsenic Trioxide in high-risk MDS. Contact: Marcin Sobocinski, MD. Phone: +48-12-424-7600.

THE NORDIC COUNTRIES

Nordic MDS Group. Maintenance treatment with 5-azacytidine in patients with advanced MDS and MDS-AML, who have obtained CR with intensive chemotherapy. An open perspective Phase II study M\NMDSG02B. Contact: Eva Hellström-Lindberg, MD, PhD. Phone: 011-46-85-858-0000.

Nordic MDS Group. Effects of anemia in MDS quality of life, cardiac function and health care costs. An open, non-randomized Phase II study NMDSG03A. Planned to start April 2004. Contact: Herman Nilsson-Ehle. Phone: 011-46-85-858-0000.

SPAIN

Hospital Clinic, Barcelona. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Benet Nomdedeu, MD. Phone: +34 93 227 55 11.

Hospital Son Llatzer, Palma de Mallorca. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Joan Bargay, MD. Phone: +34 871 20 21 38.

Hospital Universitario Del Salamanca, Salamanca. A multicenter randomized open-label parallel group Phase III trial of subcutaneous azacitidine plus best supportive care versus conventional care regimens plus best supportive care for the treatment of Myelodysplastic Syndromes (MDS). Contact: Consuelo Del Canizo, MD. Phone: +34 923 29 13 84.

To submit information on your clinical trials for publication, you can fax (609-298-0590) us at the Foundation.

Please include a contact person, a phone number, and if applicable, the trial number.

Welcome Additions to Centers of Excellence

The MDS Foundation is pleased to announce the following additions to our Centers of Excellence:

National Heart Lung and Blood Institute
Bethesda, Maryland *(Elaine Sloand, MD)*

Institute of Hematology and Blood Transfusion
Prague, Czech Republic *(Jaroslav Čermák, MD, PhD)*

Universität Hamburg
Hamburg, Germany *(Nicolaus Kröger, MD, PhD)*

University of Pavia Medical School
Pavia, Italy *(Mario Cazzola, MD)*

MDS Board of Directors

Gifts to the Foundation

The MDS Foundation relies entirely on gifts and membership fees to further its work. We would like to acknowledge the generosity of the following individuals and organizations that have recently provided gifts to the Foundation:

George C. Allen, *Ellsworth, ME*

Herbert E. Bayer, *Plainfield, IL*

H. Joachim Deeg, MD, *Seattle, WA*

Alan and Kathy Ferayorni, *Scottsdale, AZ*

Eugene and Eloise Fox, *Kensington, CA*

United Way of New York City
Ms. Susan J. Ferber Account, *New York, NY*

Geoffrey and Sandy Goldworm, *Jupiter, FL*

Harley and Mildred Grimm, *Salado, TX*

James W. Hester, *Lilburn, GA*

Mary Miyawaki, *Honil, HI*

Dr. Ellen K. Page-Robin, *Kalamazoo, MI*

Brenda Queen, *Manchester, MI*

Ronald E. Smith, *Albuquerque, NM*

The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding. If you would like to contribute or if you have a unique idea of your own, please write to us at:

36 Front Street, PO Box 353
Crosswicks, NJ 08515
or call us at 1-800-MDS-0839