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THE MDS NEWS

The Newsletter of The Myelodysplastic Syndromes Foundation

From the Guest Editor's Desk

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EIGHTH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES: A PREVIEW

Nagasaki, Japan, May 12–15, 2005

Myelodysplastic syndromes (MDS) are a group of hematological diseases evidenced by bone marrow failure (ineffective production of blood cells) and progression to leukemia. Clinical features, including patients' symptoms, are quite heterogeneous: mild anemia to severe cytopenias, with some patients suffering from leukemia, making it difficult for physicians to evaluate and monitor disease status, and choose proper treatments. MDS is becoming much more important as a hematological disorder because the incidence of MDS seems to increase along with the prolongation of life expectancy. MDS is found more frequently in the elderly than in younger people, and it has become one of the major hematological disorders. However, we do not have any clear model to explain how MDS develops or any treatment that is curative for patients with MDS. It is apparent that the challenge of MDS is enormous.

Aiming to promote better treatment for patients with MDS, the first "International Symposium on MDS" was held in 1988 at Innsbruck, Austria. In this meeting, basic and clinical researchers interested in MDS gathered and discussed many topics including their MDS studies. Participants, who now serve as part of the MDS Foundation's Board of Directors, strongly believed that it was very important for both clinicians and basic researchers to exchange state-of-the-art information in order to develop new treatments for MDS. After this first meeting, these international symposia have been held biannually in Europe or in the USA. This year, the 8th International Symposium on Myelodysplastic Syndromes will be held from May 12-15, 2005 in Nagasaki City, Japan. It is our great honor to organize this meeting in Nagasaki, the first "International Symposium on MDS" in Asia. In this symposium, a wide variety of subjects from basic research to clinical treatments will be presented and discussed by MDS specialists. It is the tradition for this 4-day symposium to preserve a plenary style of presentation so that all participants including researchers and clinicians can discuss this information and produce an active and useful interaction between "bench" and "clinic". This approach has been successful in translating new classifications and new treatments into clinical use, like the new WHO classification, cytokine therapy, immuno-suppressive therapy and other new drugs and treatment strategies. Basic researchers and young investigators will also benefit from this interaction.

Recently, some new treatments have become available for MDS, and a lot of basic research and clinical trials have been performed in MDS. Reflecting

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the progress in many fields, we received more than 180 abstracts for this 8th International Symposium meeting, and 'hot' presentations and active discussions are expected. For example, new data on the efficacy of lenalidomide in MDS was recently published (February 10 issue of The New England Journal of Medicine). We will hear the details and the extension of the trial data in Nagasaki. A demethylating agent, azacitidine, was approved by the US Food and Drug Administration for the treatment of all subtypes of MDS last year. We will also listen to information on the recent advances of this drug. In the field of etiology, the etiological role of radiation exposure will be discussed by two Japanese speakers from Hiroshima University and Nagasaki University. Both schools suffered from the Atomic Bomb 60 years ago, and the study on A-Bomb survivors will show new data about radiation exposure and MDS. Many papers regarding the molecular analysis of MDS were also submitted to this symposium. Topics on the mouse model of MDS will be presented, and these mice will be used as a nice model to analyze how MDS develops or how the molecular mechanism of leukemia transforms into MDS. This year, in the "Susanne Fleischman Memorial Lecture", Professor Timothy Quill of Rochester University will give a talk on palliative care and MDS, which will remind us of the importance of "total care" for patients with MDS and their family members.

The abstracts for this symposium were sent from many countries. We expect to have significant participation from Asian physicians. Since this is the first symposium in Asia, we strongly hope that young investigators in Asian countries take this opportunity to learn about MDS from world-famous investigators in this field.

Nagasaki city is located on the Western end of Japan, and this city has an outstanding history among many Japanese cities. From the 17th century, Japanese government ("Shogun") exercised a seclusion policy (closed the door to foreign countries) for more than 200 years, keeping Japan completely isolated from the world. But there was one exception. A small island called "Dejima" in the Nagasaki Port was the only place that Dutch merchants were allowed to stay for trade, and Nagasaki city also had a strong relationship with China because of its location. Information and goods from foreign countries passed through this city for more than 200 years. These historic backgrounds contribute to the present-day Nagasaki; an outstanding city characterized by a mixture of European, Chinese and Japanese cultures.

The Nagasaki University School of Medicine, the oldest medical school in Japan, originated from the first European-style medical school, founded in 1857 and the hospital, founded later, by a Dutch physician, Dr. Pompe.

In the recent history of Japan, during World War II, Nagasaki became an unforgettable city for all Japanese because of the Atomic Bomb on August 9, 1945. Although Nagasaki city was completely destroyed, citizens in this city re-built Nagasaki. Now in our city, you will see a mixture of different cultures in the food, the architecture you see during a walk, the festivals, and many other things. We would like the many participants attending the MDS symposium to enjoy their stay in Nagasaki.

Finally, we would like to show our deep appreciation to The Myelodysplastic Syndromes Foundation for their precious support for this 8th International Symposium on MDS. We are looking forward to seeing you in Nagasaki!

Share Your Stories With The MDS Community

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!!!

8th International Symposium on MDS

May 12–15, 2005, Nagasaki, Japan

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Symposium Website:
URL: http:www2.convention.co.jp/mds8th

Abstract and Registration Forms are available from the MDS website:
http://www.mds-foundation.org

SCIENTIFIC PROGRAM

THURSDAY, MAY 12, 2005

- **Etiology of MDS:** *David T. Bowen, Masako Iwanaga, Pierre Fenaux, Akiro Kimura*
- **Classification and Diagnosis:** *John Bennett, Ulrich Germing, Akira Matsuda*
- **Prognostic and Risk Factors:** *Zuzana Sieglova, Andrea Kuendgen, Keichiro Mihara*
- **Stem Cell Biology I:** *Tatsutoshi Nakahata, Koichi Akashi, Connie Eaves, Rose Ann Padua*
- **Stem Cell Biology II:** *Kiyoyuki Ogata, AA van de Loosdrecht, Martin Jadersten, Stephen D. Nimer*
- **Molecular Study I:** *Jaroslaw Maciejewski, Manuel Aivado*
- **Genetic Study I:** *Zixing Chen, Michael Lübbert Masashi Sanada, Maho Ishikawa*

FRIDAY, MAY 13, 2005

- **Molecular Study II:** *Stephen Nimer, H. Phillip Koeffler, Junko H. Ohyashiki*
- **Molecular Study III:** *Hiroyuki Mano, Seishi Ogawa, Kinuko Mitani*
- **Genetic Study II:** *Ying-Wei Lin, Hideo Harigae, Detlef Haase*
- **Immune Suppressive Therapy:** *Jeffrey Molldrem, Hideki Tsushima, Shinji Nakao, Chen Shuchang*
- **New Treatments I:** *Alan F. List, Michelle Le Beau, Anita Krithivas Gandhi, Azra Raza*
- **MDS in Children I:** *Charlotte Niemeyer, Atsushi Manabe, Henrik Hasle*
- **MDS in Children II:** *Ayami Yoshimi, Akira Ohara*
- ***Suzanne Fleishman Memorial Lecture:*** Hosted by *The Myelodysplastic Syndromes Foundation, Inc., Timothy E. Quill*

SATURDAY, MAY 14, 2005

- **Iron Chelation:** *Peter Greenberg, Eva Hellström-Lindberg, Peter Jensen Norbert Gattermann*
- **New Treatments II:** *Victor Hoffbrand, Richard M. Stone, Pierre W. Wijermans, Azra Raza*
- **Stem Cell Transplantation:** *Shin-ichiro Okamoto, Theo de Witte, Joachim Deeg, Guillermo Sanz*
- **Immunology:** *Haruo Sugiyama, Marcin Wojciech Wlodarski*

SUNDAY, MAY 15, 2005

- **New Treatments III:** *Ghulam J. Mufti, Lewis Silverman, Pierre Fenaux*
- **Chemotherapy:** *Shingo Yano, Elihu Estey Arnold Ganser*
- **Other Treatments:** *Sabine Knipp, Keisuke Miyazawa, Lionel Mannone*
- **Morphology Summary:** *John M. Bennett, Ulrich Germing*

From A Patient's Perspective

So You Have MDS... What Now?

Bill Bryant, MD

"…Myelodysplastic syndrome...no known cure… treatment…mainly supportive…" the doctor solemnly intones—as you sit in shock and disbelief, and immediately start wondering how long you have. You go home, more scared than despondent, to talk with your loved ones and try to make some sense of what you have heard. And as you talk, questions start to come up—questions like: "Maybe the doctor is wrong? He said there was no cure? Who is this doctor anyway? Maybe he doesn't know what he's doing? Should we get another opinion? Isn't there anything else we can do?" These are valid questions. Let's try to help you find some answers.

Your Doctor's Qualifications

Presumably the doctor you have seen is one to whom you were referred, and is a specialist in hematology, and presumably the diagnosis is based on a bone marrow biopsy. If not, it is advisable to find another doctor now. It is legal for any licensed physician to practice hematology, but you should be under the care of a doctor who is board-certified by the American Board of Hematology. This means that she has completed specialty training in internal medicine, then spent two or three additional years in a fellowship program in hematology (or hematology and oncology), and—and this is critical—passed an examination given by the American Board of Hematology to attain certification. A board-eligible doctor is one who has taken all the required training, but has not yet passed the board exam. The exam is not always given immediately upon completion of training, so maybe the doctor has not yet had an opportunity to take it. On the other hand, maybe they have taken it and failed—they can still practice as a hematology specialist without board certification. While it is true that a doctor without such certification might be a good hematologist, there is no way for you to know. So it is best to be under the care of a board-certified doctor.

Board certification is the most important of the doctor's credentials. The only other factor of importance in the doctor's educational background is where the doctor took his hematology fellowship. Most ideally, for your purposes, it would have been at one of the designated MDS Centers of Excellence (listed in this newsletter) in relatively recent years, as this would mean that the doctor has probably had considerable experience with MDS patients. Next best would probably be any other university medical center in the United States. Again, good doctors can come out of other situations, but it is wise to eliminate uncertainty wherever you can.

You should also find out about how many major hematology meetings the doctor is in the habit of attending. There is a tendency for a doctor to be either a "meeting attending doctor" or not. You want to have one of those doctors who feel compelled to keep up to date on the latest information. The doctor should probably attend at least one major hematology meeting per year—"major" meaning a multiple-day meeting of national interest.

Also important is the number of MDS patients the doctor currently has in his care, since familiarity with the problem and experience in its management is definitely of benefit in dealing with this difficult situation. In addition, imagine your doctor at one of the major hematology meetings. At such a meeting there are often courses and lectures and exhibit demonstrations going on simultaneously, and your doctor will be choosing what he wants to take in. If there is a presentation on MDS, he is much more likely to attend it if he is carrying a large number of such patients than if he hasn't seen a case in the past six months.

Your Doctor's Job

At the recent MDS patient conference held in Palo Alto, California, one of the most striking revelations was the high percentage of patients who expressed considerable dissatisfaction with their doctor. Whereas some of this dissatisfaction may be justified, let's consider the complaint "All I get from my doctor is 'I don't know'."

Firstly, it needs to be understood that MDS is not one specific disease—rather, it is failure of the bone marrow to produce blood cells in the normal manner, as determined by laboratory testing. When blood and bone marrow samples from patients diagnosed with MDS are examined under the microscope, there are many differences in the appearance of the cells, such that patients with bone-marrow dysfunction have been classified into five or six different categories, depending on certain characteristics of the cells. So all MDS is not the same—and neither

is the cause all the same. It is known that exposure to radiation, or to the chemical benzene, or to chemotherapy drugs can cause bone-marrow failure (MDS). But in the vast majority of cases, the cause is not known—and who knows how many different causative factors there may be within the category of "unknown". There may be a myriad of as yet unidentified "diseases" that can cause bone-marrow failure and are lumped into the broad category of MDS.

To imagine how difficult this is for your doctor, let us consider an analogy which is not perfect, but which may help to understand the situation. Let us compare the laboratory diagnosis MDS to the symptom "abdominal pain". Neither is a specific disease entity. Abdominal pain varies regarding the nature and location and severity of the pain. In MDS, the cells produced by the malfunctioning bone marrow look different under the microscope from one case to another. In the case of abdominal pain, examination and further testing will be required to determine the cause of the pain and establish a specific diagnosis, which will determine what treatment is expected to help. But in the case of MDS, there are no further tests that will determine a cause, and treatment is almost as difficult as it would be to treat "abdominal pain" without any further evaluation.

So when your doctor says "I don't know" you will realize that it is not their fault and that you are fortunate to have a doctor who is honest and secure enough regarding their competence that they are willing to admit that they do not know.

Regarding what your doctor can do for you, it is their job to keep up to date on all current aspects of the management of a patient with MDS. Then they must monitor your case and make appropriate recommendations regarding treatment. Unfortunately, at the present time, treatment options are quite limited. Doctors can recommend medications to try to stimulate the bone marrow to put out more blood cells, or he can recommend transfusions. And they now have an FDA approved drug called Vidaza (5-azacytidine) that has produced a positive response (not a cure) in about 15% of patients. Bone marrow transplantation may be an option for some younger patients who are in otherwise good health. And it is an important part of their job to communicate with you regarding their ongoing assessment of your case and their treatment recommendations.

Your Job

So since your doctor does not have a known cure for you, and you want to get better, someone else is going to have to take charge here, and that someone is you (perhaps with some help from family or friends). In fact, we need to put special emphasis upon the attitude with which you enter into this partnership effort with your doctor to improve your health. There is strong tendency, particularly in older Americans (and most MDS patients are older), to regard the doctor as an authoritarian figure to whom we unquestioningly submit ourselves for treatment. In general, it is more appropriate for patients to consider themselves in charge of their health care, with the doctor as a very powerful and indispensable ally. And specifically, with MDS, where medical science does not have many answers yet, leaving your doctor without much to work with, you are going to have to rely upon yourself to improve your situation. You need to have a doctor who will welcome your intense involvement, and will recognize it as help rather than a lack of confidence in their knowledge.

Knowledge

First, learn what you can about MDS in general, and keep up to date on all new developments that are made public. Your best sources of information are the Internet, and that excellent organization, the MDS Foundation, which you certainly must join. Their website address can be found elsewhere in this newsletter. Regarding other information from the Internet, be sure to check on the source of everything you find there, to see that it comes from a reputable medical center. And do not hesitate to ask your doctor questions about the information that you get. In so doing, you are of course hoping to get answers, but just as importantly, this will let the doctor know that you are an intelligent and informed patient, and that he's going to have to stay well-informed himself to stay a step ahead of you. Because in reality, knowing everything about MDS is your doctor's part of the job, and your most important job is to do everything that you can to maximize your health from a general standpoint.

It is very important to realize that your body has a natural tendency to heal itself. Throughout your entire life, your body has been constantly healing injuries, repairing the damage done by environmental toxins, fighting off uncountable numbers of bacteria and viruses, killing aberrant abnormal cells before cancer develops, and doing a good job of maintaining

reasonably good health, probably without you consciously doing much to be actively helpful. Now your body needs you to become aggressively involved in providing an atmosphere that will help it to heal. Tremendous and naturally intelligent healing power is available and provides you with an excellent chance to improve your situation. So do not be discouraged—a positive mental attitude is the necessary first step.

Knowing that you can get better, even though your doctor may not have good medicine for you, is critically important. Maybe, in fact, it is an advantage that there is no established successful medical treatment for your condition, because it gives you the opportunity to work on healing yourself through natural means, and experiencing a great deal of personal growth in the process.

In order to help your body to heal itself, you must first create conditions to promote optimum general health. This means attention to diet, exercise, stress management, emotional well-being, and spiritual growth. Unfortunately, most MDs are not well equipped to help you in these areas, particularly when your medical difficulty is not clearly related to diet, lack of exercise, stress, etc. MDs receive very little if any training in these areas, and as a result of both background and inclination, MDs tend to be oriented more toward crisis management and the treatment of disease processes with drugs. So you will need to look elsewhere for help.

In general, your major sources of information will be the Internet, bookstores, and medical newsletters. Some of your best help will come from non-traditional medical sources.

Diet

We are not using the word diet here to refer to a weight loss program, but rather we are referring to the relative amounts of various types of food that one consumes. Although diet is of critical importance regarding health maintenance and improvement, there is so much disagreement among those who are supposed to know about such things, and recommendations change so frequently, that we must presume that no matter what anybody says, much remains unknown. Probably one of the reasons for the confusion is that we are not all the same biochemically and metabolically. We therefore have differing nutritional requirements, all the way from how much of a particular vitamin we need, to what general type of diet will work best for us. It seems very possible that some day individual genetic analysis will show what specific nutrients a particular person needs, so that a diet (and supplements) can be tailored specifically for that person, which will not only maintain optimum health, but maybe even cure disease. In the meantime, we will have to do the best we can with the information and conflicting advice that is available. The following general suggestions are offered, with the understanding that new information could change this advice at any time, and again realizing that the same plan won't work for everyone.

As you seek out information yourself on the subject of diet (and it is recommended that you do) you will encounter some weird and extreme diets. These are to be avoided, in the absence of reliable information about them. In general, balance and moderation are advised until we know better.

Consider making vegetables the mainstay of your diet, as well as plenty of fruit. You perhaps do not need as much meat as most Americans usually consume. Limit your intake of saturated fats, polyunsaturated fats, and transfatty acids, making olive oil your fat staple. Choose whole grain products over those made with more refined flour. Limit your intake of sugars, including corn syrup, fructose etc. and products containing them.

Other Physicians

If, in your area, a well-trained and licensed naturopathic physician (professional designation ND) is available, she might help considerably to design a diet well-suited to you personally—a diet that could even help you to get better. In many states naturopaths are not required to be licensed, and some may be practicing with very marginal training. In fact diplomas are apparently available on the Internet, so caution is advised here. But a good ND can be quite helpful and should be willing to work with your doctor if necessary. Information regarding appropriate training and credentialing is available on line at www.naturopathic.org.

Suggested Reading

The book, "Eat Right For Your Type" by Peter J. D'Adamo, a naturopathic physician, may be of interest to you. Dr. D'Adamo's premise is that what is healthy for you to eat is determined by your blood type. Although I don't think the subject is quite as simple as that, it is my personal belief that he is onto something helpful, and that his recommendations offer a good starting point from which to experiment regarding which foods seem to agree with you.

Other

Based upon extensive reading and personal experience, it is strongly suggested that you try eliminating dairy products and wheat from your diet for at least three or four weeks. If you have any sort of allergy, such as asthma, hay fever, eczema, etc., this trial is even more strongly recommended, even though there may seem to be no direct connection between eating these things and your allergy symptoms. Both milk and wheat are known to be highly allergenic and may irritate the immune system in ways that we do not now understand, and perhaps in ways that do not result in typical allergy symptoms. If so, it seems best not to put any additional load on the already compromised immune system of the MDS patient. This suggestion is not based upon any hard science, but it can't do any harm to undergo such a trial period and see if you perceive any benefit. Probably the most direct approach is to eliminate both dairy and wheat for three or four weeks, and if you are not feeling any better you may as well resume both. If you are feeling better, you can resume one of the foods, observe the effect, and decide from there whether eliminating one or both is helpful. If you want to see whether it has any effect on your blood count, it is probably better to continue the trial for at least six weeks before checking your blood again. It should be noted that giving up dairy and wheat is quite inconvenient, since it means not taking in anything that contains these substances. In addition to the obvious things like cheese, ice cream, and anything containing flour (bread, pasta, all baked goods, most cereals, etc.), if you start reading labels you will find many preparations that contain one or both of these foods. If you do get benefit from the elimination trial, and you decide to continue, you may want to experiment to see if you can consume very small amounts of these things in commercial preparations without being bothered.

Nutritional Supplements

Vitamins and Minerals

Whether or not to take any nutritional supplements is a difficult question, since again, I believe this is an individual matter. We are referring here to taking additional amounts of substances that are normally present in the diet, such as vitamins and minerals, as well as substances that are normally manufactured by the body, such as coenzyme Q10. Hopefully you will be able to locate a naturopathic physician who can help you in this area as well. It is probably a good idea to take a high-quality multivitamin and mineral preparation but there are some who would question whether or not such artificially created nutrients are of any value when not presented to the body in their naturally occurring form, in which they are combined with many other food factors. It may be that preparations containing vitamins combined with plant phytofactors (as are the Nutrilite products) are more effective. I am not aware if this has been proven. In any event, you should avoid extremely high doses of vitamins and minerals unless you have the approval of your doctor. Also, you should get approval before taking any type of nutritional supplement other than vitamins and minerals.

Herbals

As defined here, herbs are not in the same category as nutritional supplements. The effective ingredients in herbs are substances that are not in our usual foods and are foreign to the body. Therefore they fall into the category of medicines or drugs even though they do not require a prescription. Contrary to popular opinion, herbs are not automatically safe and good for you just because they are naturally occurring. Consider the mushroom family, some members of which are used to make Asian herbal remedies and some members of which are deadly poisons. Herbs are commonly prescribed by naturopathic physicians, and practitioners of Ayurveda and Traditional Chinese Medicine, as well as by herbalists with no particular credentials. Herbs, like all medicines, can be either helpful or harmful.

The decision regarding whether or not to get involved with the taking of herbs is a difficult one, and has to be individualized, depending upon your situation. It would be unwise to take them on your own, without the recommendation of a licensed practitioner of one of the above medical systems, or a qualified naturopathic doctor. The approval of your hematologist

should be obtained, unless she has told you she has nothing more to offer you, in which case you are presumably free to try anything.

Exercise

Exercise is critically important for the acquisition and maintenance of good health, and should play an important part in your recovery program. Since the capacity for exercise varies greatly among MDS patients, we will talk in generalities here.

Walking

Probably the most beneficial exercise for all who are capable of participating is simply walking. One would like to be able to walk for up to about forty-five minutes at a fairly brisk pace—what you might judge to be about 75% of your maximum walking speed. Of course not many MDS patients will be able to do this, so you need to start out doing what you can, with the idea that duration of time is more important than speed—that is, it is better to walk slower for ten minutes than faster for five minutes. Try to increase your time by just a few minutes every week or two, if you can, but don't push yourself too hard. You do not want to use all of your limited energy for exercise, since you need some for enjoying other aspects of life, as well as for healing. As a rough guideline, you should finish your walk feeling pleasantly tired, and within an hour you should be feeling at least as good as you did before the walk, if not better. You should not get discouraged if you can't walk for very long or very fast. Walking for just five or ten minutes at a snail's pace is vastly better than not walking at all.

You need to make getting your walk a high priority, and since we all have a certain amount of inertia to overcome, you may sometimes have to push yourself to get started. You will probably find that you feel better if you walk either before breakfast, or at least two hours after eating. You have a limited number of blood cells and you need them nourishing your heart and your muscles while walking, rather than digesting your food.

Walking outdoors surrounded by nature and in relatively clean air is probably best, weather, climate, and circumstances permitting. Walking on city streets is all right if the air is not too polluted, but if pollution is high, walking indoors is probably best for MDS patients. Indoors can be in a mall, or in a gym on a treadmill. Or, if your situation involves the necessity to walk indoors much of the time, look into the possibility of getting a basic treadmill at home. You do not need an elaborate model like the gym has, since it will not be worked nearly as hard, and your needs are not sophisticated.

Strength Training

In addition to walking, it is probably advisable to do a little work with either some light weights or elastic stretch bands two or three times a week for 10 or 15 minutes to maintain upper body strength. And devoting about the same amount of time to some mild stretching exercises to help maintain flexibility can also be helpful.

Yoga / Tai Chi

Yoga and tai chi are Asian disciplines which appear on the surface to be exercise techniques, and they are very good exercise. However, their true value runs much deeper than that. They are also very meditative and spiritual disciplines, and can help improve your health from many perspectives. It is highly recommended that you research these arts, select the one that appeals to you most, and get involved. Do not let the fact that you think you are unable to perform the activities properly discourage you from getting started. The spiritual benefits will be there anyway, and physical benefit will come from just making the effort. Tai Chi is a form of Chi-gong (which will be discussed in detail later) and there are other ways to practice Chi-gong that are much less demanding than Tai Chi and are also very beneficial.

Stress Management

The connection between stress and disease states is well established. It is important to minimize and get control of stress for two reasons: to maximize your chance for improvement in your health, and to make your life more enjoyable. Firstly, you need to identify and list the causes of stress in your life, and then make whatever changes you can in order to eliminate or minimize those factors. There will probably remain some stress producing circumstances over which you have no control. I believe that the best way to deal with residual stress is through meditation. We are not talking about sitting down and thinking about your problems. We are talking about any one of a number of definite meditative techniques. Perhaps the most recognized one is known as Transcendental Meditation, recognizable because it is a money making business enterprise that has been heavily marketed in the past. Once one gets past the ritualistic initiation into the society run by the self-styled Maharishi Mahesh Yogi, it can be a useful

technique to help clarify thought processes and deal with stress. However, there are many other methods that are at least as good, and can be learned without cost. Most meditative techniques involve sitting quietly for periods of twenty or more minutes. There are people who have tried meditating and find that they just can't sit still for that long, and some even experience unpleasant and stressful reactions when they try. If you are a person who prefers to keep moving, there are still excellent meditative techniques available to you. Some examples include meditative yoga, mindful walking and other mindful activities from the Buddhist tradition, and Chi-gong (including Tai Chi) from ancient China. We are not all the same, and the same method of meditation will not suit everyone, so some research into various techniques will be necessary, but I think you will find the results to be well worth the time and effort.

Spiritual Growth

In addition to helping relieve stress, meditation has another huge benefit in terms of helping to develop spiritual awareness. It is difficult to understand and explain how this comes about, but I think if you begin to practice meditation, and stay with it for a while, you will experience this phenomenon. Spiritual growth is an essential factor in your quest to improve your health and must not be overlooked. Organized religion and going to church may or may not be a part of it for you, since again we are not all the same. If you are one of those whose spiritual growth has been stunted by some of the behavior of organized religion, please note that the problems are not in the Message, but are due to the actions of people who didn't get the Message right. So let's not throw the baby out with the bathwater. If you are one who has trouble accepting the concept of a personified deity, as in the Judeo-Christian or Islamic traditions, you might investigate Buddhism, a philosophy that is extremely spiritual without the establishment of a personified deity. Actually, there is much help to be obtained from basic Buddhistic philosophy for persons of any religious persuasion, and if such things interest you, looking into the teachings of the original Buddha might be worthwhile.

Mind-Body-Spirit Connection

The existence of a mind-body-spirit connection is very real, despite the fact that it is a poorly understood area. Even those holistic practitioners who believe in this sort of thing and work with patients accordingly could not tell you how this connection works, and many doctors either deny or ignore the existence of such connections. Anyone who doubts the power of the mind-body connection needs only to consider the well-known placebo effect. When a patient takes a substance as a medication, thinking that it may be helpful, a favorable response is often obtained, even though medical science has no reason to think that the substance would have any effect at all, beneficial or otherwise. This is the placebo response, and it gives strong support to the existence of the mind-body connection. Because medical science cannot explain how the placebo response works, some doctors scoff at it and imply that it is an indication that there is something wrong with the patient's mental processes. In reality there is something wrong with the doctor who is not aware of the fact that his mission is to improve the condition of the patient whether he understands the mechanism of action or not, and if that can be accomplished with the absolute safety of a placebo, everyone wins. The problem, of course, is that the placebo response doesn't always work. But neither does any accepted medical treatment, and the fact that the response exists at all should stimulate extensive research. For help in the area of mind-body-spirit connection, you are referred to the work of Joan Borysenko, a respected pioneer in this field. Start at her website, www.joanborysenko.com.

Guided Imagery

One way that you can use the mind-body-spirit connection for your benefit is through the process of guided imagery. A simplified explanation of guided imagery is that it involves assuming a meditative state and then visualizing your body doing things to heal itself, generally with the help of a person certified in this art. Considerable information and help locating a certified practitioner in your area can be obtained from the Academy for Guided Imagery in Malibu, CA, at website www.academyforguidedimagery.com. You can, however, gain considerable benefit from guided imagery without a practitioner. I most highly recommend the outstanding guided imagery audiotapes and CDs produced by Image Paths Inc., accessible at website www.healthjourneys.com. They consist of beautiful meditative background music along with narration by Belleruth Naparstek, the very talented psychotherapist, writer, and lecturer who is the creator of this group of over forty titles. The benefits of several of these titles have been

researched and verified at dozens of academic medical centers. Which ones of these can be of help to you will depend upon your individual situation, as you will see when you view the selections.

Energy Healing

An area foreign to practitioners of Western medicine is that of working with what Eastern healers call chi, (also written qi) which is life energy or life force—whatever it is that separates living things from inanimate objects. There are several disciplines that are based on working with chi. They have their basis in the theory that chi flows throughout the body along certain pathways, and that disease states occur when the proper flow of chi becomes disrupted and its distribution in the body becomes unbalanced. Talented and experienced healers claim to be able to feel the presence of chi in the patient, and to sense its imbalances. Treatment involves restoring the proper flow and balance of chi, which should help to recover from the illness. The problem is that since there are not generally accepted methods for scientifically identifying and measuring chi, many practitioners of Western medicine do not believe that these energy-healing disciplines have anything to offer. However, most patients who get involved with a well-qualified energy healer will tell you that at the very least their treatments make them feel better, and this alone is worth quite a lot in terms of quality of life. The two energy-healing disciplines best known in the U.S. are reiki and chi-gong.

Reiki

In reiki, the practitioner uses his own hands to move the chi around in the patient, attempting to restore proper flow and balance. This is a valid discipline that can be of some benefit to some patients, but unfortunately it has been the victim of unprofessional promotion in the U.S. over that past several years. For example, if you go online, you will find that you can "Become a Reiki Master within 48 hours for $67". So if you decide to look into reiki, be sure that the practitioner that you consult has a history of at least several years in the active practice of the art.

Chi-gong

Chi-gong is a much more complex healing discipline that comes to us from ancient China, and I believe it to be more powerful then reiki. As mentioned, chi is "life energy", and gong can be translated as "work", so chi-gong means "working with life energy". There are many styles of chi-gong that have developed from different schools of thought in China over the centuries, but there are certain commonalities. Chi-gong can be used for health maintenance, or to treat disease. Chi-gong treatment can be externally applied by a practitioner, or self-applied by the patient, or both. In external chi-gong treatment, a practitioner actively instills chi into the patient, and then assists in its proper circulation. When chi-gong treatment is self-applied, the patient actively practices a discipline aimed at acquiring and circulating chi. This is of great importance because many studies have shown the value of the "intent to heal", and the patient's own application of this intent may be very helpful. (The beneficial effect of the "intent to heal" is well demonstrated by the placebo effect discussed earlier.) The patient's active involvement consists of a system of exercises that incorporate three modalities: physical movement, breathing techniques, and mental focus, all to acquire chi and to promote its proper flow through the body. It is part of the practitioner's job to assist the patient in the learning of these techniques. Part of the value of chi-gong is that the physical movement involves exercise (even if it were to have no other value), and the mental focus involves both meditation and a form of guided imagery, both recommended earlier.

Chi-gong is highly recommended because it offers the potential for considerable help. I have personally witnessed an experienced chi-gong healer using an external technique (which he developed) to treat an elderly man with advanced Parkinson's disease. The patient had a severe tremor of both upper extremities, the typical depressed-looking fixed facial expression, and walked with a labored shuffle. Within about two minutes, and without the healer touching the patient, the tremor stopped completely, the patient's face broke out in a wide smile, and he began talking animatedly as he stood up and began walking—still like an old man, but much better than before. When the patient's astonished daughter asked the healer if her father were cured, he said "Once in awhile the miracle happens, but probably not." He said that most likely the patient would slip back into his prior condition at some unpredictable time, most likely within hours, or maybe later. Nevertheless this was powerful evidence that a chi-gong healer is definitely able to influence a disease in a favorable way, and that chi-gong is a modality that deserves our attention. And it cannot be overemphasized that unless one pursues chi-gong to a ridiculous extreme, there is no way that it can be harmful.

For anyone wishing to learn more about chi-gong, Kenneth S. Cohen is a highly knowledgeable, ethical, and scientifically inclined practitioner, teacher, and writer. His website address is www.qigonghealing.com. His book, "The Way of Qigong", is highly recommended, whether or not a qualified practitioner is available to help you.

Other Disciplines

Acupuncture

Acupuncture is another healing discipline that probably would not be harmful to an MDS patient, but I would not expect it to be particularly helpful unless it is administered by a chi-gong or Traditional Chinese Medicine practitioner, as a part of an overall program.

Homeopathy

Homeopathy would probably not be harmful, and even though it seems to help some patients in some situations, I would not expect it to benefit an MDS patient.

Ayurveda

Ayurveda, which originated in India, is one of the world's oldest medical art forms. It is a valid discipline, but some of those practicing it in the U.S. have had minimal training and have been certified by an organization started by the Maharishi Mahesh Yogi of Transcendental Meditation fame. This training program has also been a big money-making enterprise for the Maharishi. There are, however, legitimate practitioners, but this system relies heavily on the prescription of herbal remedies and your hematologist might not approve of that approach since there would seem to be the possibility of the herbs doing harm. The same holds true for Traditional Chinese Medicine.

Interacting With Your Doctor

Having determined that your doctor is professionally competent, what else is important? Most patients want a doctor with whom they feel they can communicate well. Communication problems can stem from language barriers, or cultural differences, or some people, doctors included, are just not good communicators. If your doctor is foreign-born and either speaks with such a heavy accent that you find it hard to understand him, or seems culturally predisposed to not communicating with patients, consider changing doctors. Political correctness is not a consideration here. If your doctor speaks intelligibly, but you feel you just don't communicate well, you might consider diplomatically bringing this up with the doctor. Your doctor will probably make more of an effort in this regard. In fact, bring up anything that makes you unhappy with regard to your care. Do not hesitate to ask the tough questions. Many doctors are not used to assertive patients, but most will respond favorably to a patient who is friendly, polite, and brings these things up in a non-hostile, matter-of-fact way. The key is friendly and polite, and conveying the attitude that you are anxious to work with the doctor as a team. Contrary to what some may think, doctors are people too, and if they think you are a nice and reasonable person, they naturally want you to like and approve of them. On the other hand, if your attitude comes across as hostile and demanding, you are much less likely to get a favorable response, because the doctor would probably rather have you go elsewhere.

Your doctor needs to understand and accept the fact that you may be involved with disciplines outside the realm of conventional medicine in an effort to help yourself. You need to make them aware that they are still your primary doctor, and that these outside efforts should be regarded as complementary rather that alternative. Your doctor needs to be reassured that you will not take any herbs or mega-doses of supplements without their approval.

This brings up the question of how to ask for this approval. It is best not to ask "What do you think about my taking …?" or "Do you think it would help me to take…?" When the question is phrased this way they are very likely to say no. Rather it is suggested that you say something like "The naturopathic doctor thinks I would benefit from taking… do you have any reason to think that it would be harmful?" The doctor is likely to think that the substance will not help you, but that is not what you asked, and there is a better chance that you will get approval if it is something you want to try.

You need to have a doctor who will appreciate the fact that you are working hard to do what you can to improve your health. Many doctors may think that some of the suggestions in this article are worthless, but hopefully your doctor is open-minded enough to realize that sometimes patients can benefit by forces that science does not yet understand. And the physician should also realize that none of the things suggested can do you any harm, as long as you check before taking anything.

Second Opinions

We need to discuss the issue of second opinions. Anytime that you are not comfortable with your doctor's recommendations you should consider getting a second opinion. The most likely times to request one would be at the time of diagnosis, and when treatments are recommended. Your doctor should be receptive to the idea of a second opinion, and should not object. It would be quite acceptable for your doctor to say something like "This particular issue is not really controversial, and I think you would be wasting your time, but it is certainly alright for you to get a second opinion if you wish". Any serious objection to your obtaining one is a reason to change doctors. In seeking a second opinion, it is important to be sure that you will have confidence in it, so it is advisable to get it from one of the MDS Centers of Excellence, even if it means a trip of some length. Do not go with the attitude that the second opinion doctor has to start with a clean slate. Be sure to have your doctor supply copies of your records as well as blood and bone marrow specimens since that may avoid some repetition, and the response you have to any prior treatment may be important in helping decide what to do next.

If treatment is recommended, find out how much experience your first doctor has had with the recommended modality. If it is quite limited, and the MDS Center has had more experience, you might want to go there for the treatment. Or, if that is not feasible, find out if your doctor and the MDS Center are both willing to work together and have your primary physician administer the treatment under their guidance from afar.

An important thing to remember is that just because treatment is recommended does not mean that you must go through with it. After all, it is your health and your life at stake, and you are in charge. So ask the tough questions. It has been recommended because it might "help" you. Find out the percentage chance of it "helping", and how much and what kind of help might be anticipated? For example, maybe there is a chance that it will improve your blood count, but it may make you feel bad in the process, and if you do get any help, how long would it be expected to last? And what are the chances that the treatment might make you worse? Chemotherapeutic agents run the risk of lowering your blood count, and it is already too low. If that happens, how do you decide whether or not to persist with treatment? If treatment lowers your blood count, what are the chances that it will recover or at least return to pre-treatment levels? In effect, what are the chances that treatment will shorten your life, and/or diminish its quality?

It is suggested that you find out the name of the medication being recommended and go on line to find out as much as you can about it, and then ask your doctor to clarify anything that you do not understand. Please realize that these questions are not posed to influence you not to have any treatment. Rather, since you will be making what may be crucial decisions, and by gathering all of the information that you can, you are in a better position to weigh all factors and arrive at a decision that is comfortable. Also, keep in mind that if you feel you have good doctors and they are recommending treatment, this factor should enter into the decision-making process.

Finally, on the issue of treatment, what should you do if you are offered the opportunity to participate in a clinical trial for a new drug? Again, you have to ask the tough questions. First, you need to know what the chances are that you will actually receive the drug being tested? Clinical trials almost always involve control subjects as well as subjects receiving treatment. Depending upon the particular study, you might receive the drug being tested, or you might receive another drug for comparison purposes, or you might get only a placebo. Your chance of receiving the drug being tested may be no better than one in four. You also need to know whether the drug is one that has already been tested, and if so, what were the results? And whether further testing involves a different dose? Perhaps it is combined with another drug? If so, has that drug been tested before and what were the results? You would also like to know what benefits might be anticipated, and what other risks are involved, while realizing that these factors may be quite uncertain with a new drug.

Conclusion

I truly believe that if you follow some of the suggestions in this article, that at the very least you will feel better. Actually, how you feel is probably more important than your blood count. Hopefully by following some of these suggestions you will help your situation to stabilize, or maybe even improve, and thereby allow you more time. Not only is more time desirable in itself, but also each day brings you closer to new developments which might offer you more help yet.

Whether you decide to follow any of these suggestions or not, you must read the book

Spontaneous Healing by Andrew Weil, MD. Dr. Weil is a graduate of Harvard Medical School who has devoted his career to the study and practice of complementary and alternative medicine. Dr. Weil is Chairman of the Department of Integrative Medicine at the University of Arizona Medical School. To get acquainted with his work, visit his website at www.drweil.com. And be sure to read *Spontaneous Healing*. It will encourage you with the knowledge that you can get better, and give you the hope that you need to begin the process.

The MDS Foundation would like to thank Dr. Bryant for sharing his unique insight with other MDS patients.

The author of this article, Bill Bryant, is 71 years old and has been retired since 1999 after practicing for 34 years as an ophthalmologist (eye physician and surgeon) in Sacramento, CA. In January of 1998 he was told that he had refractory anemia, a type of MDS, with low red cells, neutrophils, and platelets. A few months later it was determined that he also had large granular lymphocyte leukemia, an even more rare condition for which there also was no established reliably effective treatment. The relationship between the conditions is uncertain, but about 5% of patients with this type of leukemia also have MDS. Because of the rarity of this situation, the prognosis was unknown. Since then he has had no treatment other than self-imposed adherence to some of the disciplines described in this article. Blood counts gradually went down for the first few years, then stabilized, and for the past two years have been improving, so that at present they are not notably worse, and in some respects are slightly better than at the time of diagnosis over seven years ago. He still walks about 2 1/2 miles daily, except for two days a week when he walks 18 holes of golf on full-length courses. He spends considerable time studying complementary and alternative medicine. He feels that he is pretty much normally active, though he does tire more easily and requires more rest than he did prior to these diagnoses.

Regarding this article, Dr. Bryant says: "What I wrote is what I believed when I wrote it, but things change so fast that I reserve the right to change my mind about anything at any time, including yesterday".

MDS Foundation Plans 2005 Initiatives

The MDS Foundation is committed to making a significant contribution to the advancement in understanding and of accurately diagnosing the myelodysplastic syndromes. We will be focusing our efforts in the following initiatives for the upcoming year:

- **CME Awareness Program**
- **MDS Foundation Charity Golf Tournament August 1, 2005**
  Supported by grants from:
- **MDS Practice and Treatment Registry**
- **The International Working Group on MDS Morphology**
- **MDS Patient's Quality-of-Life Forums**
- **Transfusion Burden Initiative**
  Supported by a grant from:
- **Patient Sero-Therapy Registry**
  Supported by a grant from:
- **Center of Excellence Patient Support Groups**
- **MDS Awareness Event with Mia Hamm April 15, 2005**
  Supported by a grant from:

Pfizer has provided the MDS Foundation with an educational grant to support the Foundation's work.

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
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

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

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

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

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

Georgetown University Hospital
Lombardi Comprehensive Cancer Center
Washington, DC
Ekatherine Asatiani, 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
Phoenix, Arizona
James L. Slack, MD

Mayo Clinic
Jacksonville, Florida
Alvaro Moreno-Aspitia, MD

Mayo Clinic
Rochester, Minnesota
Louis Letendre, MD

MCP Hahnemann University
Philadelphia, Pennsylvania

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

Mount Sinai School of Medicine
New York, New York
Lewis R. Silverman, MD

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

New York Medical College/
Westchester Medical Center
Zalmen A. Arlin Cancer Center
Valhalla, New York
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
Peter T. Curtin, MD

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

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

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 Children's Research Hospital
Memphis, Tennessee
Gregory Hale, MD

Thomas Jefferson University
Kimmel Cancer Center
Philadelphia, Pennsylvania
Emmanuel C. Besa, 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 New Mexico
Health Sciences Center
Albuquerque, New Mexico
Robert Hromas, 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

University of Texas Southwestern Medical School
Dallas, Texas
Amit Verma, MD

University of Wisconsin, Madison Medical School
Madison, Wisconsin
Mark B. Juckett, MD

Wake Forest University School of Medicine
Comprehensive Cancer Center
Winston-Salem, North Carolina
Istvan Molnar, 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, Michigan
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

Ankara University
Evangelismos Hospital
Ankara, Turkey
Osman Ilhan, MD

Athens University
Evangelismos Hospital
Athens, Greece
Theofanis Economopoulos, MD

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

Fundeni Clinical Institute
Bucharest, Romania
Radu Gologan, MD, PhD

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

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

Hôpital Avicenne/University Paris XIII
Bobigny, France
Pierre Fenaux, MD

Hôpital Claude Huriez, CHU Lille
Service des Maladies du Sang
Lille, France
Bruno Quesnel, MD

Hôpital Cochin/University Paris V
Paris, France
Prof. Francois Dreyfus, PU-PH

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

Hospital de Santa Maria
Lisbon, Portugal
João F. Lacerda, MD

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 Cermák, MD, PhD

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

Johann Wolfgang Goethe University
Frankfurt Main, Germany
Johannes Atta, 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 Universität
Munich, Germany
Torsten Haferlach, MD

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

Nippon Medical School
Tokyo, Japan
Kiyoyuki Ogata, MD, PhD

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

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

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

Rigshospitalet
National University Hospital
Copenhagen, Denmark
Lars Kjeldsen, MD, PhD

Royal Bournemouth Hospital
Bournemouth, United Kingdom
Sally Killick, MD

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

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

Tel-Aviv Sourasky Medical Center
Tel-Aviv, Israel
Moshe Mittelman, MD

Tokyo Medical College
Tokyo, Japan
Kazuma Ohyashiki, MD

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

Universität Hamburg
Hamburg, Germany
Nicolaus Kröger, MD, PhD

Universitätsklinikum Carl Gustav Carus
Dresden, Germany
Uwe Platzbecker, MD

University of Århus
The University Hospital
Århus, Denmark
Johan Lanng Nielsen, MD, PhD

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

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

University Hospital Benjamin Franklin
Berlin, Germany
Wolf–Karsten Hofmann, MD, PhD

University Hospital of Innsbruck
Innsbruck, Austria

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

46th ASH Annual Meeting Highlights

San Diego, California
December 4–7, 2004

The Foundation was very pleased that ASH placed a strong emphasis on the myelodysplastic syndromes this year. On Saturday, December 4th a press conference was held on *Emerging Issues in Hematology: Expert Perspectives on Myelodysplastic Syndromes*. Dr. Alan List served as the Moderator and panelists included Dr. Steven Gore, Associate Professor of Oncology, Johns Hopkins University School of Medicine, Baltimore, MD; Elihu Estey, MD, Chief of the Acute Leukemias and Myelodysplastic Syndromes Section, The University of Texas MD Anderson Cancer Center, Houston, TX; Peter Emanuel, MD, Director of the Comprehensive Cancer Center, University of Alabama at Birmingham, Birmingham, AL; and Stephanie Lee, MD, Assistant Professor of Medicine, The Dana-Farber Cancer Institute; Boston, MA.

Dr. List began the discussion with a brief background about the myelodysplastic syndromes and the biological and clinical advances that are occurring in MDS. Dr. Gore spoke about the role of gene methylation and the impact that the approval of Vidaza® (5-azacitidine) has had in MDS. Dr. Emmanuel highlighted a different type of demethylating agent, decitabine, which is used in advanced MDS. Dr. Estey discussed the oral farnesyltransferase inhibitor (Zarnestra™), combination therapies, and where it fits into the traditional treatment for higher-risk MDS patients. Dr. Lee was the last presenter and she spoke about the importance of patient-physician communication and how that interaction can help or hurt patients. Dr. List pointed out that it is a very exciting time in MDS research, because we have a great number of new agents and the research momentum is gaining strength. A question and answer session was then conducted at the end of the presentations.

In addition, the Foundation held a satellite symposium on Friday, December 3, 2004 entitled *"Targeting the Clone – the Basis for Therapeutic Evolution?"*

We would like to thank Drs. Michaela Fontenay, Steven Gore, Michelle M. LeBeau, and Alan F. List for participating on the Faculty of this symposium.

This program generated excellent audience interest and attendance.

For a copy of the CD ROM, which contains all of the slide presentations from this session, please contact the MDS Foundation at 800-MDS-0839.

The MDS Foundation's booth was extremely well attended and the focus of many hundreds of ASH participants.

At the annual Board of Director's meeting, Dr. Hussain Saba was presented with a plaque from Dr. John Bennett recognizing his outstanding service to the goals and programs of the MDS Foundation for over a decade, 1994–2004. Dr. Saba serves as Director, Clinical Research for Malignant Hematology Program, H. Lee Moffitt Cancer Center and Research Institute, Tampa, Florida.

At the ASH meeting, Novartis presented their Phase III data for ICL670, their investigational once-daily oral iron chelator.

Novartis Investigational Drug ICL670 Demonstrates Positive Results in Treating Chronic Iron Overload, A Potentially Life-threatening Condition

- **Phase III trial in regularly transfused patients shows doses of 20 and 30 mg/kg/day to be highly effective while doses of 5 and 10 mg/kg/day not effective**
- **Treatment with ICL670 results in highly statistically significant ($P<0.001$) absolute reduction in liver iron concentration**
- **Global submission anticipated for first half 2005 with Orphan Drug status in US and EU**

East Hanover, December 6, 2004 – The investigational drug ICL670, an oral, once-daily iron chelator, demonstrated significant efficacy at maintaining or reducing absolute liver iron concentration (LIC), an accepted indicator for total body iron content, when used at doses of 20 and 30 mg/kg/day in a Phase III trial. However, the overall trial primary endpoint of non-inferiority to deferoxamine was not met because doses of 5 and 10 mg/kg/day were not effective.

Data from three studies were presented at the annual meeting of the American Society of Hematology in San Diego, California.

As a once-daily oral treatment, ICL670 is designed to be easier to use and more convenient than deferoxamine (Desferal®), the current standard iron chelation therapy, which typically requires slow infusion by pump over eight to 12 hours for at least five days a week. Additionally, ICL670 was generally well tolerated in both adults and children as young as age two years, with most adverse events being mild to moderate in severity. The ICL670 global clinical trials program is the largest ever prospectively implemented for an investigational iron chelator.

Iron overload is a cumulative, potentially life-threatening condition that may result from repeated blood transfusions required to treat certain types of anemias, including sickle cell disease, thalassemia and myelodysplastic syndromes. Over time, if left undiagnosed or untreated, iron overload can lead to debilitating and life-threatening consequences, including damage to the liver, heart and endocrine glands.

"This is a wonderful potential advancement in the treatment of chronic iron overload and could extend the benefits of chelation therapy to many patients who are not currently being treated," said Diane Young, MD, vice president and global head of Phase II/III Clinical Development at Novartis Oncology. "Additionally, as the first once-daily oral treatment, ICL670 has the promise to free patients from the burden of daily subcutaneous infusions of therapy."

Study Details

The international, open-label, randomized, multicenter Phase III study included 586 patients with beta-thalassemia and transfusion-related iron overload who were randomized to receive ICL670 or deferoxamine according to a fixed dosing regimen. According to LIC at baseline, patients were randomized in a 1:1 ratio to receive either oral ICL670 once daily at doses of 5, 10, 20 or 30 mg/kg, or subcutaneous deferoxamine at doses of 20–60 mg/kg/day for 5 days/week.

The primary endpoint of the trial was the achievement of a specified reduction in liver iron concentration (LIC) after one year of therapy. Those with lower initial LIC values on the deferoxamine arm were permitted to remain on their pre-study doses and were compared to patients receiving the lower doses of 5 or 10 mg/kg/day of ICL670. Therefore, many of these individuals received significantly higher doses of deferoxamine relative to ICL670.

Because of the disproportionately low dosing of patients with ICL670 at 5 and 10 mg/kg/day when compared to deferoxamine, non-inferiority was not achieved in the overall population. Non-inferiority was demonstrated, however, in those patients treated with ICL670 at 20 and 30 mg/kg/day.

The ICL670 trial showed a highly statistically significant ($P<0.001$) absolute reduction of LIC in the overall patient population studied. Data demonstrated that after one year of treatment, the mean overall change in LIC from baseline was -5.3 ± 8.0 mg Fe/g dry weight (dw) for patients taking doses of 20 and 30 mg/kg/day of ICL670. Patients being treated with comparable doses of deferoxamine achieved a reduction in LIC of -4.3 ± 5.8 mg Fe/g dw.

In a related, open-label Phase II trial presented at ASH, data from a study of 184 patients with myelodysplastic syndrome (MDS), other rare anemias, and patients with thalassemia unable to take deferoxamine therapy, also demonstrated

maintenance or reduction of absolute LIC values in patients treated with ICL670 at doses of 20 and 30 mg/kg/day.

In these studies, ICL670 was generally well tolerated with the most frequently reported adverse events being nausea, vomiting, diarrhea, abdominal pain, skin rash and mild stable increases in serum creatinine, usually within the normal range. No unmanageable toxicities have been observed.

No cases of agranulocytosis, a potentially life-threatening hematological adverse event, were reported in the ICL670 trials (more than 800 patients received ICL670). In the Phase III trial, four patients (1.4%) in the deferoxamine group and eight patients (2.7%) in the ICL670 group had discontinued therapy due to any adverse events.

Based on the positive results of these studies, Novartis anticipates submitting ICL670 in the first half of 2005 for registration with health authorities worldwide for the treatment of patients with chronic iron overload due to blood transfusions. The U.S. Food and Drug Administration granted fast-track status in 2003 for ICL670 in this patient population. A drug designated as a fast-track product is intended for the treatment of a serious or life-threatening condition and demonstrates the potential to address unmet medical needs for the condition.

Additionally, ICL670 was granted Orphan Drug status in the US and EU in 2002. In the US, the term “Orphan Drug” refers to a product that treats a disease that affects fewer than 200,000 people in the US. In the EU, the term “Orphan Drug” refers to a product that treats a serious or life-threatening disease that affects fewer than five people per 10,000 population. The intent of the Orphan

Drug designation is to stimulate the research, development, and approval of products that treat rare diseases.

The foregoing release contains forward-looking statements that can be identified by terminology such as “investigational drug,” “potentially,” “anticipated,” “designed to,” “can lead,” “potential advancement,” “could extend,” “has the promise to free,” “anticipates,” or similar expressions, or by discussions regarding potential regulatory approvals of ICL670, potential revenues from ICL670, or regarding the long-term impact of a patient’s use of ICL670. Such forward-looking statements involve known and unknown risks, uncertainties and other factors that may cause actual results with ICL670 to be materially different from any future results, performance or achievements expressed or implied by such statements. There can be no guarantee that ICL670 will be approved for any indications, or will achieve any particular level of revenues, in any market. Neither can there be any guarantee regarding the long-term impact of a patient’s use of ICL670. In particular, management’s ability to ensure satisfaction of the health authorities’ requirements is not guaranteed and management’s expectations regarding commercialization of ICL670 could be affected by, among other things, additional analysis of ICL670 clinical data; new clinical data; unexpected clinical trial results; unexpected regulatory actions or delays or government regulation generally; the company’s ability to obtain or maintain patent or other proprietary intellectual property protection; competition in general; and other risks and factors referred to in the Company’s current Form 20-F on file with the U.S. Securities and Exchange Commission. Should one or more of these risks or uncertainties materialize, or should underlying assumptions prove incorrect, actual results may vary materially from those anticipated, believed, estimated or expected. Novartis is providing the information in this press release as of this date and does not undertake any obligation to update any forward-looking statements contained in this press release as a result of new information, future events or otherwise.

Additional Information

Full prescribing information on Desferal is available at www.pharma.us.novartis.com/product/pi/pdf/desferal.pdf.

Save the Date: The 2nd Annual MDS Foundation Charity Golf Tournament

Clear your calendar! The date is set! August 1st, 2005, will mark our 2nd Annual Charity Golf Tournament to be held at Olde York Country Club in Chesterfield NJ. This Gary Player signature course will be the host once again to a full field of both amateur (that's us) and Professional golfers (that's Bruce Fleisher, his friends, and any one else carrying a PGA card in their wallet that day).

Senior PGA Professional, Bruce Fleisher, providing golf tips during last year's MDS Charity Tournament on Hole #11, Par 3, at Olde York Country Club.

This is a must attend event! Senior PGA Professional, Bruce Fleischer, is returning this year to be our Master of Ceremonies. Reflecting on last year's golf tournament, Bruce suggested bringing additional professional help! The MDS Foundation will be welcoming Senior PGA Professionals Jay Siegel, Jim Thorpe, Bob Toske, and Bobby Wadkins; LPGA Professional, Michele McGann; Joe Thiesman, former Washington Redskins Quarterback, and Jim Palmer, three-time Cy Young Award Winner and Baltimore Oriole baseball Hall of Famer. They'll gladly offer their expertise in a two hour-long clinic before the tournament begins. The clinic will include small group instruction with these Pro golfers. Following, there will be 18 holes of golf, lunch and an opportunity to win fabulous gifts on any one of the designated golf holes! Each Senior PGA, LPGA, and Celebrity guest, will join all the competing foursomes and each participating group will get to play with several professional and celebrity guests. The MDS Foundation cordially invites you to bring your "A" game that day.

A Cocktail Reception and Dinner will follow the tournament. An informative talk from several expert speakers will present the latest research in MDS, and the importance of MDS Awareness. Concurrently, a Silent Auction will enable golfers to bid on fantastic golf equipment that will enhance your game as well as other terrific prizes. All proceeds from the auction will benefit the MDS Foundation and their initiatives. Look for future announcements and invitations with more specific information as the time nears. And don't forget to practice!

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!

OTHER SITES OF INTEREST:

ASBMT™ American Society for Blood and Marrow Transplantation:
www.asbmt.org

International Bone Marrow Transplant Registry:
www.isbmtr.org

National Marrow Donor Program®:
www.marrow.org

Blood & Marrow Transplant Information Network:
www.bmtinfonet.org

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.

MDS CLINICAL TRIALS ANNOUNCEMENT

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 Syndromes, 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.

MethylGene Inc., of Montreal, initiated the first of two dose-escalating Phase I trials for MGCD0103 in hematological cancers. MGCD0103 is a rationally designed isotypic selective small-molecule inhibitor of histone deacetylase. The second hematologic cancer trial is scheduled to be initiated in early 2005. Both trials will evaluate the safety, pharmacokinetics, pharmacodynamics and tolerability of MGCD0103 in patients with leukemias or myelodysplastic syndromes.

Novartis. Phase I, open-label, dose escalating study to evaluate the safety, biologic activity and pharmacokinetic profile of LAQ824 in patients with relapsed or refractory AML, CLL, or CML in blast crisis, or advanced MDS. The primary objective of this study is to determine the Maximum Tolerated Dose (MTD) and Dose Limiting Toxicity (DLT) of LAQ824 as a single agent when administered by intravenous infusion as outlined in the protocol.

Novartis. An Open-label Phase II Trial of PKC412 Monotherapy in Patients with Acute Myeloid Leukemia and Patients with Myelodysplastic Syndromes PKC4122104. Patients who agree to participate in this trial will be screened for the FLT3 mutation. If positive, they will have a physical exam, blood test, EKG, chest x-ray, bone marrow aspirate and a pregnancy test.

Novartis. Phase II, open-label trial evaluating the safety and efficacy of Deferasirox for treatment of transfusional iron overload in adult patients with Myelodysplastic Syndromes. Planned to start February 2005.

Trials with ICL670 are anticipated to begin in early April. Please contact 800-340-6843 in early April for more information.

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).

Schering-Plough Research Institute. P02978. A Pivotal Randomized Study of Lonafarnib (SCH 66336) Versus Placebo in the Treatment of Subjects With Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia. The purpose of this study is to determine clinical benefit of Lonafarnib plus best supportive care versus Placebo plus best supportive care, measured as achievement of platelet transfusion independence.

This Phase III trial will start in spring 2005 and be conducted at approximately 60 sites in US, Canada, Europe, Latin America, Far East. Contact: Sabine Loechner, e-mail: sabine.loechner@spcorp.com; or Mary Sugrue, MD, e-mail: mary.sugrue@spcorp.com.

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

Contact www.clinicaltrials.gov to learn more about other trials for Myelodysplastic Syndromes. Type in "myelodysplastic syndromes" in "Search Clinical Trials" then click on the "Search" button to obtain a listing.

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 and Blood Institute of the Desert, Rancho Mirage, CA. Phase I/II study of arsenic trioxide in combination with cytosine arabinoside in patients with MDS. Contact: R. Lemon. Phone: 760-568-4461.

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.

Case Western Reserve University, Cleveland, OH. CWRU-5Y97. Phase II trial using umbilical cord blood to evaluate the efficacy of transplantation to treat aplastic anemia and myelodysplastic syndromes patients. Eligible patients must have disease not responsive to medical therapy. Contact: Mary J. Laughlin. Phone: 216-844-8609.

Cedars-Sinai Medical Center, Los Angeles, CA. 02287. Phase II Trial of Paricalcitol in Myelodysplastic Syndromes 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. Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndromes. Contact: Liz Kuczkowski. Phone: 216-445-3795.

Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC. Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndrome (CCCWFU 29304). Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Comprehensive Cancer Center of Wake Forest University, Winston-Salem, NC. CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndrome: Phase II trial using cholecalciferol (Vitamin D3) to evaluate the efficacy of 2000 IU Vitamin D3 daily for 6 months to treat MDS. Eligible patients must have MDS; IPSS score 0–1.0; life expectancy >1 year; no other concurrent therapy for MDS; no history of hypercalcemia. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Comprehensive Cancer Institute. Huntsville, AL. Phase II study of arsenic trioxide (Trisenox) in patients with MDS. Contact: J.M. Waples, MD. Phone: 256-551-6546.

Dana-Farber Cancer Institute, Boston, MA. Phase I Study of Vaccination with Lethally Irradicated, Autologous Acute Myeloblastic Leukemia Cells Engineered by Adeonviral Mediated Gene Transfer to Secrete Human Granulocyte-Macrophage Colony Stimulating Factor in Patients with Advanced Myelodysplasia or acute Myelogenous Leukemia. This is a study to determine the feasibility of preparing lethally irradiated autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with myelodysplasia or acute myelogenous leukemia. The study will also investigate the safety and biologic activity of vaccination with lethally irradiated, autologous myeloblastic leukemia cells engineered by adenoviral mediated gene transfer to secrete GM-CSF in patients with advanced myelodysplasia or acute myelogenous leukemia. Contact: Ilene Galinsky. Phone: 617-632-3902.

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.

Fox Chase, BMT Program, Philadelphia, PA. 3297. Phase II trials using fludarabine-based regimen to evaluate the efficacy of mini-allogeneic blood stem cell transplantation to treat myelodysplastic syndromes. Eligible patients must have HLA identical donor available, be under age 70 and platelet or red cell transfusion dependent. Patients with matched related donors will be considered up to age 70 with Karnofsky Performance Scale >80%. Patients with matched unrelated donor will be considered to age 65 only. Contact: Marge Bellergeau, RN. Phone: 215-214-3122.

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 #1809. 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 patients (<50 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. Uses a combination of ATG and cyclophosphamide (CY) for the conditioning of patients with AA who are transplanted from HLA-identical family members. Contact: R. Storb, MD. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #800. Uses a combination of ATG, CY and low dose (200 cGy) TBI for conditioning of patients with AA (up to 55 years of age) to be transplanted from unrelated donors. 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.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1628. Uses a targeted busulfan plus cyclophosphamide approach for conditioning. G-CSF-mobilized peripheral blood cells will be partially T-cell depleted with the intent of reducing the GVHD frequency and severity. Eligible are patients with MDS or high-risk AML who have an HLA-identical sibling donor. Contact: A. Woolfrey. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1913. Combines targeted busulfan with fludarabine plus Thymoglobulin. This protocol enrolls patients with MDS, myeloproliferative disorders, and other myeloid diseases. The objective is to further reduce non-relapse mortality. Patients with related and unrelated donors will be eligible. Contact: P. O'Donnell Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1668. Uses combinations of fludarabine and low-dose TBI for the conditioning of "older" patients or patients with clinically significant co-morbid conditions to be transplanted from related or unrelated donors. Contacts: M. Maris, B. Sandmaier. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1872. Uses a combination of ATG given for 4 days, followed by intermittent injection of Enbrel for patients with low or intermediate-1 risk disease by IPSS. Generally these are patients with <10% marrow blasts. The ATG is administered at the Center; the administration of Enbrel can be done by the patients themselves at home or in your office. Contact: B. Scott. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1888. Uses a combination of Enbrel plus arsenic trioxide (Trisenox) in patients with more advanced MDS (generally IPSS intermediate-2 or high risk) or patients who have failed to respond in Protocol #1872. Contact: B. Scott. Phone: 206-288-1024.

Fred Hutchinson Cancer Research Center, Seattle, WA. FHCRC #1926. Uses a combination of Enbrel plus 5-azacitidine (Vidaza) for patients with advanced MDS or patients who fail to respond to treatment in Protocol #1872. The Protocol is currently being reviewed by the IRB. Contact: B. Scott. 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.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13935. Phase I/II Trial of Subcutaneous Decitabine. Optimizing Genomic Methylation in patients with Myelodysplastic Syndrome (MDS). Opening soon. Contact: Wendy Hodapp. Phone: 813-745-1706.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13937. A Pharmacokinetic and Pharmacodynamic Study of Oral CC-5013 in Subjects with Low or Intermediate-1 Risk Myelodysplastic Syndromes. Open. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13727. A Phase IA/II, two-arm, multicenter, dose-escalation study of LBH589 administered intravenously on two dose schedules in adult patients with advanced hematologic malignancies. Inclusion criteria: Patients with a cytopathologically confirmed diagnosis of AML. MDS, (RAEB, RAEBT), ALL, CLL, CML, multiple myeloma, NHL including CTCL who are either relapsed after or refractory to standard therapy, and are considered inappropriate candidates for standard therapy. Patients with a cytopathologically confirmed diagnosis of AML. MDS, (RAEB, RAEBT) who are previously untreated but due to age, poor prognosis, or concurrent medical conditions are considered inappropriate candidates for standard induction therapy, or those who refuse standard induction therapy. Contact: Wendy Hodapp. Phone: 813-745-1706.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 14154. SCIOS–A randomized, multicenter, open-label, modified dose ascension. Parallel study of the safety, tolerability, and efficacy of oral SCIO-469 in patients with MDS. Pending. Contact: Stacy Moss. Phone: 813-745-8391.

H. Lee Moffitt Cancer Center, Tampa, FL. MCC# 13346. A randomized, placebo-controlled, double-blind trial of the administration of the MDR Modulator, Zosuquidar Trihydrochloride, during conventional induction and post-remission therapy in patients >60 years with newly diagnosed AML, Refractory Anemia with Excess Blasts in Transformation, or High-Risk Refractory Anemia with Excess Blasts. Contact: Wendy Hodapp. Phone: 813-745-1706.

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. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be > 60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Judith Karp. Phone: 410-502-5399.

Johns Hopkins Oncology Center, Baltimore, MD. J0051. Dose finding study of Bryostatin-1 and GM-CSF in Refractory Myeloid Malignancies. Contact: Lisa Malick. Phone: 410-502-0735.

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 (MDS) and Acute Myeloid Leukemia (AML). Contact: Caryn Salito. Phone: 410-502-7114.

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. J0443. A dose-Finding Trial of the Histone Deacetylase Inhibitor MS-275 in Combination with 5-Azacytidine (5AC, NSC 102816) in patients with Myelodysplastic syndromes (MDS), Chronic Myelomonocytic Leukemia, and Acute Myeloid Leukemia (AML). Contact: Tianna Dauses. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J0254. Phase I study of Flavopiridol in timed sequential combination with Cytosine Arbinoside and Mitoxantrone for adults with poor-risk Acute Leukemias and Myelodysplasias. Contact: Jackie Greer. Phone: 410-614-1329.

Johns Hopkins Oncology Center, Baltimore, MD. J0466. Phase I and Pharmacological trial of 17-Allylamino-17 Demethoxygeldanamycin (17-AAG) and Cytarabine in Refractory Leukemia and Myelodysplastic Syndrome. Contact: Caryn Salito. Phone: 410-502-7114.

Johns Hopkins Oncology Center, Baltimore, MD. J0330. Phase I study of Flavopiridol in combination with Imatinib Mesylate in Bcr/Abl+ Hematological Malignancies. Contact: Tianna Dauses. Phone: 410-502-7110.

Johns Hopkins Oncology Center, Baltimore, MD. J0434. Phase II study of VNP40101M for patients with Acute Myelogenous Leukemia or high-risk Myelodysplasia. Contact: Jackie Greer. Phone: 410-614-1329.

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: 713-563-4613.

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.

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

MD Anderson Cancer Center, Houston, TX. ID99-059. 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. 04-H-0112. 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.

New York Medical College/Westchester Medical Center, Valhalla, NY. Pivotal randomized study of Lonafarnib Versus Placebo in the treatment of subjects with MDS or CMML who are platelet transfusion dependent with or without anemia. Contact: Dr. Karen Seiter. Phone: 914-493-7514.

New York Medical College/Westchester Medical Center, Valhalla, NY. Log 6252. Phase I/II study of a non-myeloablative regimen of pentostatin, mitoxantrone and cytarabine for engraftment of allogeneic hematopoetic progenitor cells in patients with acute leukemia, chronic myelogenous leukemia and myelodysplasia: The mini allo protocol. Contact: Dr. Delong Liu. Phone: 914-493-7514.

New York Presbyterian Hospital, New York, NY. Phase I/II trial of Trisenox in combination with low dose Ara-C for the treatment of high-risk MDS and poor prognosis AML in patients >60 years. Contact: Gail Roboz, MD. Phone: 212-746-3126.

Oregon Health & Science University, Portland, OR. 8346. Phase 1-2a Study of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes (MDS). Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 7944. A Randomized, Double-blind Trial of Fluconazole vs. Voriconazole for the Prevention of Invasive Fungal Infections in Allogeneic Blood and Marrow Transplant Patients. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8186. A Phase III Randomized, Multicenter Trial Comparing G-CSF Mobilized Peripheral Blood Stem Cell with Marrow Transplantation from HLA Compatible Unrelated Donors. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8343. Prolonged Mycophenolate Mofetil and Truncated Cyclosporine Postgrafting Immunosuppression to Reduce Life-Threatening GvHD after Unrelated Donor Peripheral Blood Cell Transplantation using Nonmyeloablative Conditioning for Patients with Hematologic Malignancies and Renal Cell Carcinoma—A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 7881. Donor Lymphocyte Infusion for the Treatment of Malignancy After Hematopoietic Cell Transplantation Using Non-Myeloablative Conditioning—A Multicenter Trial. Contact: Peter Curtin, MD. Phone: 503-494-5058.

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: 503-494-5058.

Oregon Health & Science University, Portland, OR. 4352. Transplantation of Unrelated Donor Marrow or Placental Blood Hematopoietic Stem Cells for the Treatment of Hematological Malignancies. Contact: Peter Curtin, MD. Phone: 503-494-5058.

Oregon Health & Science University, Portland, OR. 8119. 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: Peter Curtin, MD. Phone: 503-494-5058.

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.

Roswell Park Cancer Institute, Buffalo, NY. RPC-02-03. Treatment of anemia in patients with low-and intermediate-risk MDS with darbepoetin alfa. Multicenter, phase II trial also open at the University of Alabama (Birmingham), Loyola University Medical Center (Chicago), and Rochester General Hospital (Rochester, NY). 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.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2000-08. Pilot Study to Test The Efficacy of Gleevec (STI 571) in Patients with Myelodysplastic Syndromes. Given the clinical and molecular similarities between CML and CMMoL, especially those related to the activation of tyrosine kinase induced downstream events suggest that suppression of the same kinase in CMMoL by using an agent like Glivec may produce clinical benefit in these individuals. We propose to test this hypothesis by treating one cohort of 15 CMMoL patients with Gleevec or STI571 at 400 mg po daily. The second cohort of 15 patients [having translocation (5;12)] will likewise receive Gleevec or STI571 at 400 mg po daily. Response assessment will be made every 8 weeks and in case of disease progression, the patient will be removed from the study. Responding patients or those with stable disease will be treated for one year at least with the drug provided by Novartis. After the one-year period, further therapy will depend upon the discretion of the physician. Disease progression is defined as occurrence of acute leukemia, increase in BM blasts by 50% over pre-therapy values if the blast count was >5% to begin with, and worsening cytopenia. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS 2002-04. Pilot Study to Test the Efficacy of a Combination of Gleevec with Thalidomide in Patients with Idiopathic Primary Myelofibrosis, Myelofibrosis with Myeloid Metaplasia and Myelodysplastic Syndromes Who Present With Myelofibrosis. We propose to use a combination of thalidomide and Gleevec for the treatment of patients with MMM and MDS who present with Grade 3+ and greater myelofibrosis. The rationale for this combination is that the anti-angiogenic and anti-TNF effects of thalidomide may be potentiated by the anti-TGF-b, anti-PDGF effects of Gleevec

to reduce marrow fibrosis in this group of patients. We propose to treat 30 patients on this study using Thalidomide starting at a dose of 100 mg per day and increasing to 400mg per day and Gleevec at 600mg per day. Treatment will be continued for one year or until disease progression. Bone marrows will be obtained at 16 weeks and then at the end of the study. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Rush-Presbyterian-St. Luke's Medical Center, Chicago, IL. MDS2003-01. Pilot Study to Determine the Clinical Efficacy of Coenzyme Q10 in Patients with Myelodysplastic Syndromes. We propose to treat 40 patients belonging to RA and or RARS or low risk and Int-1 categories of MDS patients with CoQ10 at a starting dose of 300 mg escalating as tolerated to 1200mg po qday. Patients will begin taking 300mg po BID with meals for Days 1–3. On Days 4–6, patients will take 300mg po TID with meals. On Day 7 and onward, patients will take 300mg po QID with meals. Patients will be treated for up to a year unless intolerable side effects and/or disease progression are noted. Responses will be continuously evaluated by weekly CBCs and bone marrows repeated every 16 weeks. Contact: Laurie A. Lisak, MMS. Phone: 312-563-2535.

Stanford University Medical Center, Stanford, CA. Phase I/II trial: Decitabine treatment of MDS. Eligibility: IPSS High, Intermediate-2. Contact: 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 DARBEPOETIN ALFA in patients with MDS. Phase II trial. Eligibility: IPSS Low, Intermediate-1. Contact: Sylvia Quesada, R.N. Phone: 650-725-4041.

Stanford University, Stanford, CA. Phase II trial: Exjade (ICL670) oral iron chelator treatment of MDS patients with iron overload. Contact: Kathy Dugan, RN. Phone: 650-723-8594.

St. Francis Hospital, Hartford, CT. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Bilgrami. Phone: 860-714-4680.

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'-deooxycytidine) 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: Ronda Waldrop. 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: Ronda Waldrop. 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: Ronda Waldrop. Phone: 972-566-7790.

Thomas Jefferson University, Philadelphia, PA. A multicenter, single-arm, open-label study of the efficacy and safety of CC-5013 Monotherapy in RBC transfusion-dependent subjects with Myelodysplastic Syndromes. Contact: Emmanuel C. Besa, MD. Phone: 215-955-0356.

Tufts-New England Medical Center, Boston, MA. Reduced intensity bone marrow transplantation as curative therapy for Myelodysplastic Syndromes. Patients under the age of 75 in good physical health with an eligible donor may participate. Contact: Geoffrey Chan, MD. Phone: 617-636-2520.

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 Chicago, Chicago, IL. 11884A. High-dose cytarabine/mitoxantrone followed by autotransplantation for therapy-related MDS. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 2978. A pivotal randomized study of Lonafarnib (SCH 66336) vs. placebo in the treatment of subjects with Myelodysplastic Syndromes (MDS) or Chronic Myelomonocytic Leukemia (CMML) who are platelet transfusion dependent with or without anemia. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 13172B. Phase 1-2a of TLK199 HCl Liposomes for Injection in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

University of Chicago, Chicago, IL. 12981A. A Phase II study of an oral VegF receptor tyrosine kinase inhibitor (PTK787/2K222584) (IND #66370, NSC #719335) in Myelodysplastic Syndromes. Contact: Margaret Green, RN. Phone: 773-702-0267.

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 Michigan Comprehensive Cancer Center, Ann Arbor, MI. Phase II trial of combination therapy with arsenic trioxide (Trisenox) and gemtuzumab ozogamicin (Mylotarg) for the treatment of adult patients with advanced myelodysplastic syndrome. Contact: Harry P. Erba, MD, PhD.

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 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.

Vanderbilt University Medical Center, Nashville, TN. Phase II study of arsenic trioxide in myelodysplasia. Contact: Shubhada M. Jagasia, MD. Phone: 615-322-4752.

Wake Forest University School of Medicine, Winston-Salem, NC. CCCWFU-29203. Orthomolecular Vitamin D in Low-Risk Myelodysplastic Syndrome: Phase II trial using cholecalciferol (Vitamin D3) to evaluate the efficacy of 2000 IU Vitamin D3 daily for 6 months to treat MDS. Eligible patients must have MDS; IPSS score 0-1.0; life expectancy >1 year; no other concurrent therapy for MDS; no history of hypercalcemia. Contact: Istvan Molnar, MD. Phone: 336-716-5847.

Wake Forest University School of Medicine, Winston-Salem, NC. CCCWFU-29304. Phase II Study of Arsenic Trioxide and Dose-Escalated Cholecalciferol in Myelodysplastic Syndrome: The purpose of this study is to determine how many patients with myelodysplastic syndrome (MDS) respond to the combination treatment with arsenic trioxide and cholecalciferol (vitamin D3). All MDS patients are eligible if they have a life expectancy of at least six months. Arsenic trioxide is administered daily for 5 days intravenously (as a "loading" dose) followed by twice a week administration. Vitamin D3 is given at 100 microgram/day by mouth and the dose is increased by 50 microgram/d every three months up to a year in patients who have no toxicity and did not achieve complete remission. Bone marrow samples are obtained before and during treatment to look at response with morphological and biological parameters. Patients may remain on the study for up to one year. 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.

Washington University School of Medicine, St. Louis, MO. This study seeks individuals with bone marrow failure. Participants are asked to submit a sample of blood for gene and telomere analysis. Researchers are investigating the hTR gene found on chromosome 3. Participants are also asked to submit their medical and family history information. This information is used to make correlations among the participants' clinical features and the gene and telomere analysis. Contact: Jennifer Ivanovich, MS. Phone: 314-454-5076.

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

Peter MacCallum Cancer Centre, 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: John F. Seymour, MD. Phone: +613 9656 1697.

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.

BELGIUM

Cliniques Universitaires Saint-Luc, Bruessel. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy

(other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemo-therapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Ferrant. Phone: 32 2 764 1810 (1880).

ENGLAND

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Cloretazine in high grade MDS. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Zarnestra in high grade MDS & AML. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Revlimid in 5 Q-Syndrome. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. Reduced intensity conditioned transplantation in MDS using Fludara, IV Campath and Busulphan as conditioning. Contact: Professor Ghulam J. Mufti. Phone: 44 (0) 207-346-3080.

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.

Kings College Hospital/Guys-Kings-Thomas School of Medicine. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. 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. 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.

FRANCE

Groupe Français des Myelodysplasies. A phase II multi-center study of treatment of anemia in low risk MDS by the combination of Epo and all-trans retinoic acid. Contact: Lionel Ades, MD. Phone: +33 1 48 95 70 55/51. lionel.ades@avc.aphp.fr

Groupe Français des Myelodysplasies. A phase II multi-center study of Thalidomide at low dose for the treatment of patients with IPSS low or Intermediate-1 risk Myelodysplastic. Contact: Didier Bouscary, MD. Phone: +33 1 40 51 65 43. bouscary@cochin.inserm.fr

Groupe Français des Myelodysplasies. A phase II multi-center study of treatment of anemia in low risk MDS by Darbepoetin Alpha. Contact: Lionel Mannone, MD. Phone: +33 4 92 03 58 46. mannone.l@chu-nice.fr

Groupe Français des Myelodysplasies. A phase III randomized trial comparing 5 azacytidine and conventional treatment (best supportive care alone, or with low dose AraC , or with intensive chemotherapy). Contact: Pierre Fenaux, MD pierre.fenaux@avc.ap-hp.fr

Groupe Français des Myelodysplasies. A phase II study of intensive chemotherapy combined to quinine in high risk MDS with PGP expression. Contact: P. Fenaux or S. de Botton. s.de-botton@voila.fr

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.

Institute Paoli Calmettes, Marseilles. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Norbert Vey, MD. Phone: +33 4 91223695.

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.

Chu 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.

Hôpital 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 Düsseldorf. 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.

Heinrich-Heine University Düsseldorf. Phase II Trial of Valproic Acid as a Monotherapy or in Combination with All-trans Retinoic Acid for the treatment of Myelodysplastic Syndromes. Contact: Norbert Gattermann, MD. Phone: +49 211 811 6500.

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.

University Hospital Benjamin Franklin, Berlin. SAKK 33/99. Antithymocyte Globulin (ATG) and Cyclosporine (CSA) to treat patients with Myelodysplastic Syndrome (MDS). A randomized trial comparing ATG & CSA with best supportive care. Contact: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

University Hospital Benjamin Franklin, Berlin. Phase II clinical trial using vaccination with Wilms-Tumor-Gen 1 (WT1) derived peptide in patients with acute myeloid Leukemia and Myelodysplastic Syndrome. Contact: Prof. D. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

University Hospital Benjamin Franklin, Berlin. AZA PH GL 2003 CL 001. A 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: Prof. Dr. Wolf-K. Hofmann. Phone: +49-30-8445-5903.

Universitätsklinikum Carl Gustav Carus, Dresden. AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trials for subcutaneous Azacitidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of MDS. Contact: Uwe Platzbecker, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 06011 (EORTC). 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: Uwe Platzbecker, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 2003/4. Radioimmunotherapy with Re-188-anti-CD66-antibody for conditioning of AML and MDS patients above the age of 55 prior to stem cell transplantation. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

Universitätsklinikum Carl Gustav Carus, Dresden. 2003/2. Tacrolimus and Mycophenolate mofetil as Graft-versus-Host disease Prophylaxis for patients with Myelodysplastic Syndrome (MDS) or Acute Myeloid Leukemia (AML) receiving conditioning with Fludarabine and targeted intravenous Busulfan and Hematopoietic stem cells from HLA-compatible siblings or unrelated donors. Contact: Martin Bornhäuser, MD. Phone: +49-351-458-2321.

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. AZA PH GL 2003 CL 001. A 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. 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.

JAPAN

Nippon Medical School, Tokyo. IRB2002-22. Open-label study of the safety and efficacy of Thalidomide in patients with Myelodysplastic Syndrome. Contact: Dr. Kiyoyuki Ogata. Phone: 81-3-3822-2131 (Ext. 6321).

THE NETHERLANDS

Universitaire Ziekenhuis Gasthuiberg, Leuven. CLI-033. A Phase II study of VNP40101M for patients with acute myelogenous leukemia or high-risk myelodysplasia. Patients with high risk myelodysplasia must be >60 years old and cannot have received prior cytotoxic chemotherapy (other than hydroxyurea) for treatment of their myelodysplasia. Low-dose single-agent araC, decitabine or 5-azacytidine regimens will not be considered prior cytotoxic chemotherapy for the purpose of this study. Prior treatment with Mylotarg is excluded. Contact: Dr. Verhoeft. Phone: 011-32-16-346880.

University of Nijmegen, Nijmegen. AZA PH GL 2003. CL 001. A 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: Dr. P. Muus. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EBMT200502. A prospective 2×2 randomized multicenter study evaluating the role of remission-induction and consolidation chemotherapy prior to allogeneic transplantation and of G-CSF mobilized peripheral blood progenitor cells versus bone marrow stem cells using HLA-identical siblings in patients with Myelodysplastic Syndromes and between 5% and 20% bone marrow blasts. Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06011. Intravenous low-dose decitabine versus supportive care in elderly patients with primary MDS (>10% blasts or high-risk cytogenetics), secondary MDS of CMMOL who are not eligible for intensive therapy. Contact: Dr. P. Muus. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EPO 2003. A Phase 2 clinical trial to evaluate the feasibility of treatment with Aranesp in patients with Myelodysplastic Syndrome (MDS). Contact: Prof. Dr. T. de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06013. Idarubicin and Ara-C in combination with Gemtuzumab-Ozogamicin (IAGO) for young untreated patients, without an HLA identical sibling, with high risk MDS or AML developing after a preceding period with MDS during 6 months duration. Contact: Prof. Dr. T de Witte. Phone: +31-24-3614762.

University of Nijmegen, Nijmegen. EORTC 06023. Randomized Phase II trial with Infliximib (Remicade) in patients with Myelodysplastic Syndrome and a relatively low risk of developing acute leukemia. Contact: Dr. P. Muus. Phone: +31-24-3614762.

THE NORDIC COUNTRIES

Nordic MDS Group. NMDSG02B. Phase II study on maintenance treatment with Azacytidine in patients with advanced MDS and MDS-AML, who have obtained CR with intensive chemotherapy. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

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

Nordic MDS Group. AZA PH GL 2003 CL 001. A multicenter, randomized, open-label, parallel-group, Phase 3 trial of subcutaneous Azacytidine plus best supportive care versus conventional care regimens plus best supportive care for treatment of Myelodysplastic Syndromes. Contact: Dr. Eva Hellström-Lindberg. Phone: 011-46-85-858-0000.

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.

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.

An Update:

The MDS Foundation will soon be working with the European Hematology Association's MDS Working Group (EHA) to standardize information on clinical trials in Europe. This will aid physicians and patients in identifying and contacting centers about participating in these trials. We'll keep you up to date!

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.

United States Congressman Robert T. Matsui Dies from MDS

Our deepest condolences are extended to the family and friends of Congressman Matsui.

The Myelodysplastic Syndromes Foundation would like to acknowledge the loss of politician and humanitarian, the Honorable Robert T. Matsui.

Congressman Matsui had been diagnosed a few months ago with MDS. He was a California Democrat who had represented Sacramento in the U.S. House since 1979. At the time of his death at age 63, he was the third-ranking Democrat on the House Ways and Means Committee.

Matsui was a major force on Social Security and international trade issues who had also authored the landmark bill passed in 1988 that awarded payments to Japanese Americans held in internment camps during World War II.

"Bob Matsui was a dedicated public servant and a good and decent man who served with distinction and integrity in the U.S. House of Representatives for more than 25 years," President Bush said in a statement released by the White House.

The MDS Foundation shares the grief of his family, friends, co-workers, and constituents at his passing.

Blood & Marrow Transplant Newsletter

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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 these diseases. 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 Audrey Hassan our Patient Liaison at 1-800-MDS-0839.

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 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.

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 12–15, 2005 in Nagasaki, Japan.

A major Foundation effort is our international information network. This network provides patients with referrals to Centers of Excellence, contact names for available clinical trials, sharing of new research and treatment options between physicians, and extension of educational support to both physicians and patients.

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

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*

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.

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CRC Press. 800-272-7737
When ordering, use code PAO50203

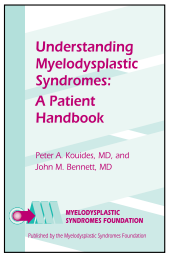
This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimens, adverse environmental and genetic factors, and efficient modalities of supportive care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

A NEW CME PROGRAM AVAILABLE IN CD-ROM FORMAT

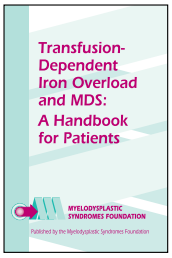
The Myelodysplastic Syndromes: Controversies in Classification and An Optimistic Look at New Treatment Options.

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.



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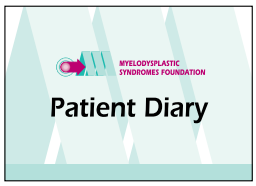


C.

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

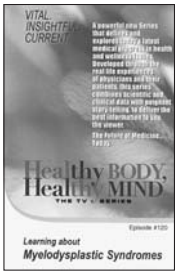
B. Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
Published by The Myelodysplastic Syndromes Foundation

C. Patient Diary
Published by The MDS Foundation

D.

D. Your Journal: Learning About Myelodysplastic Syndromes (MDS)
Supported by a grant from Celgene Corporation.

Translations available in Spanish, French, Polish, Czech, Japanese, German and Portuguese.



E.

***E.* PBS Program Videotape**
Healthy Body, Healthy Mind: Learning About Myelodysplastic Syndromes

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

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, P.O. 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

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
(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 and 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

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.

A Living Endowment donation has been made in honor of:

Nate Dunlap's 80th Birthday

This donation has been submitted by:

Edward and Barbara Muehleck
Jamesville, NY

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 the Foundation's 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 visit our website at http://www.mds-foundation.org.

The John Peter Murphy Research Fund

A memorial fund has been established by the Myelodysplastic Syndromes Foundation in the name of John Peter Murphy. The Murphy family made a decision to honor their loved one by establishing this fund to be used for research.

Donations have been made by:

Mr. and Mrs. L.G. Taber
Cranford, NJ

Arthur and Anne Morgan
Westfield, NJ

Paul and Susan Kujawski
Westfield, NJ

David and Elisha Monzella
Fanwood, NJ

Bruce and Lisa Supovitz
Owings Mills, MD

MBNA America Bank
Wilmington, DE

Ms. Gloria Kestenbaum
Teaneck, NJ

The United Stations Radio Networks
New York, NY

ClearChannel Worldwide
San Antonio, TX

Media America
New York, NY

Arthur and Anne Morgan
Westfield, NJ

Obadiah Ostergard
Wilmington, DE

James Higgins
New York, NY

Frank and Lorraine Rodgers Family Foundation
Westfield, NJ

Judy Greenstein
New York, NY

Doris Taber
Cranford, NJ

Kathy Gordeuk
Cranford, NJ

The MDS Foundation is very grateful for the heartfelt support of the family and friends of John Peter Murphy. Our work as a non-profit organization depends on public funding. If you would like to contribute in this way, or if you have a unique idea of your own, please write to us at PO Box 353, Crosswicks, NJ 08515 or call us at 1-800-MDS-0839.

The Pamela A. Rouse Research Fund

The Vallejo First Church of the Nazarene and the community of Vallejo, California made a $10,000.00 donation to honor the life of Pamela A. Rouse by establishing this fund to be used for research. Pam was diagnosed in March of 2003 with secondary acute myeloid leukemia (AML). After reviewing medical records, doctors said that she had probably gone undiagnosed for years with MDS. Her two sisters and other family members were not matches for a bone marrow transplant, so a bone marrow drive was held in early September 2003 at her church. The response of the community was astounding. In addition to paying for all testing supplies for nearly seven hundred people, the community raised an additional $10,000.00 with the hope, from her family and friends, that further research will prevent families from losing loved ones to this devastating disease.

Suzanne Fleischman Memorial Fund for Patient Advocacy

New donations have been made by:

Roslyn Raney, *Menlo Park, CA*
Fay Wanetick, *Pittsburgh, PA*

In Memorium

A memorial fund has been established in the name of

Ms. Jacquelin Rae Anderson

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

Roland Masuo
Reno, NV

Mark & Patricia Ostrem
Milton, MA

Robert Cabes
Houston, TX

Bruce Branscomb
Lamoille, NV

Vance Cummings
Fargo, ND

A memorial fund has been established in the name of

Mr. Lewis G. Armstrong

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

Ken and Diane Billanti, Carmel, IN

Gordon and Mary Ann McCallister
Carmel, IN

Ann and Henry Bernton
Portland, OR

DFAS-IN TSO Staff Employees
Indianapolis, IN

Nancy Smithberg
Kankakee, IL

Majorie H. Patterson
Carmel, IL

Beth Harrison
Indianapolis, IN

Susan Nemeth
Inidianapolis, IN

Don Warren
Lake Forest, CA

Ray and Marlene Seaton
Albuquerque, NM

Kevin and Kristina Riemer
Carmel, IN

Edward and Carol O'Brien
Willingboro, NJ

Roger and Perilynn McMichael
Carmel, IN

Donna Armstrong
Carmel, IN

David and Sharon Tunink
Carmel, IN

Robert and Carol Scher
Carmel, IN

Sandra Albrecht
Audubon, NJ

A memorial fund has been established in the name of

Mr. Robert James Beams

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

Mr. & Mrs. Joseph Goodman, Freehold, NJ

Mr. and Mrs. Royal Legault, Forked River, NJ

A memorial fund has been established in the name of

Mr. Glenn Beeson

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

Sean Gillespie
Scottsdale, AZ

Doug and Rebecca Pruitt
Phoenix, AZ

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 and Mary Ellen Bena, *Malta, NY*

A memorial fund has been established in the name of

Mr. Roger A. Brown

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

Robert and Elizabeth Pike
Boothbay, ME

Sarah Farrington and Family
Narberth, PA

A memorial fund has been established in the name of

Mr. Larry Conn

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

James and Patricia Rasey
Prosser, WA

Shelley and Ralph Neate
Santa Cruz, CA

John and Linda Hansen
San Joaquin, CA

John and Josephine Estep
Carmel, CA

Mr. Larry Conn *(continued)*

Lavorato, House, Chilton, Lavorato & Lavorato, *Salinas, CA*

Russ and Irene McCallion
Carmel Valley, CA

Sports & Leisure Travel, LLC
Palo Alto, CA

James and Sandra Heuerman
Carmel, CA

Gordon and Judy Thurston
Coalinga, CA

Don and Marjorie Kerr
Coalinga, CA

C.K. and Donnette O'Neill
Coalinga, CA

Edwin and Joan Lowry
Carmel, CA

William and Blanche Scheidecker
Carmel, CA

Wells Fargo Bank
Fresno, CA

Robert and Lee Berg
Lafayette, CA

William Pucheu
Tranquillity, CA

Gilman, Harris & Travioli
Visalia, CA

Dr. and Mrs. Allen Woodhour
Carmel, CA

A memorial fund has been established in the name of

Ms. Helen Couch

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

Kathleen and Michael Couch, *Decatur, GA*

A memorial fund has been established in the name of

Mr. James DiCave

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

Bridget DiCave
Holmes, PA

Renee Sokolovich
Eddystone, PA

Michael Silva
Wilmington, DE

A memorial fund has been established in the name of

Mr. Clarence "Bud" Dotzenroth

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

Fern and Anthony Walch
Farmington Hills, MI

Eisenberg Financial Group, Inc.
Naples, FL

Larry and Diana Lutz
Milford, MI

James and Joanne Kirchoff
East Tawas, MI

David Fortier
Savannah, GA

Janice Leonard
Naples, FL

Marge LeBuda
Farmington Hills, MI

Isabel and Norman Dotzenroth
Ontario, Canada

Karen Dotzenroth-Rickert
Ontario, Canada

Gloria Wiseman
St. Clair Shores, MI

Robert and Beverly Sudek
Livonia, MI

Mario and Mary Galasso
Northville, MI

Michael Szczerba
Commerce Twp., MI

Martie and Preston Ports
Naples, FL

Barbara Lichy
Naples, FL

Harold and Elizabeth Mistele
Naples, FL

David and Laurie Carter
Commerce Twp., MI

A memorial fund has been established in the name of

Ms. Doris Faski

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

Colchester Lions
Colchester, CT

Flora Arndt and Selm Temel
Old Greenwich, CT

John and Judy Wantroba
Ocean, NJ

Norman and Nina Lotstein
Stamford, CT

John and Eugenia Miller
Hollywood, FL

Dorothy Chiaramonte
Norwalk, CT

WT and Dorothy Nakaoka
Aurora, CO

William and Lillian Philippon
Berlin, CT

Madge Weisberg
White Plains, NY

Kevin Wojcik and Lynn Dolan
S. Glastonbury, CT

Booz Allen Hamilton Inc.
McLean, VA

Arthur Selkowitz
Stamford, CT

Linda St. Thomas
Columbia, MD

A memorial fund has been established in the name of

Mr. Robert Freyder

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

David and Josephine Belpedio
Overland Park, KS

Robert Yarosz
Arlington Heights, IL

IEEVC, Shawnee Mission, KS

William O'Reilly and Family
Stevens Point, WI

Douglas and Dianna Boston
Geneva, IL

Dick and Jean Doub
Wilmette, IL

Mike, Becky, and Corbin King
Leawood, KS

Richard and Mary Murphy
Des Moines, IA

Max and Linda Martz
Beatrice, NE

Jonathan and Kathleen Fudge
Urbandale, IA

Michael and Judith Martz
Upper Arlington, OH

The Tamblyn Family
Leawood, KS

Gunty & McCarthy Law Firm
Chicago IL

A memorial fund has been established in the name of

Ms. Jennifer Gallagher-Welch

Donations have been made in Ms. Gallagher-Welch's memory by:

Jean Nelting, *Ocala, FL*

A memorial fund has been established in the name of

Ms. Rita Goldstein

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

Levitt Weinstein Memorial Chapels, *N. Miami Beach, FL*

A memorial fund has been established in the name of

Mr. Roger D. Griswold

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

Southeastern Local School District, *South Charleston, OH*

A memorial fund has been established in the name of

Mr. William Hesson

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

Bob and Susan Parkins
Cheyenne, WY

Ellen and Jerry Cromack
New York, NY

Jack Shickich and Ann Herz
Houston, TX

Jane and Robert Cabes
Houston, TX

James and Judith Wilson
Cheyenne, WY

Tad and Ann Herz
Englewood, CO

Robert and Shirley Larson
Cheyenne, WY

Keith and Patricia Pregal
Sparks, NV

Wyoming Education Association
Cheyenne, WY

Terrance and Janet Croco
Amana, IA

A memorial fund has been established in the name of

Ms. Erma Hollingshead

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

John and Lisa Woodfin, *Vallejo, CA*

A memorial fund has been established in the name of

Ms. Joyce Jackman

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

Esther Spealman
Eugene, OR

Duane Davis
McMinnville, OR

Muriel Slemp
McMinnville, OR

Linda Carlson
McMinnville, OR

Dwayne and Marjorie Clevenger
McMinnville, OR

Dick and Norma Wiser
McMinnville, OR

A memorial fund has been established in the name of

Mr. David Joslyn

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

Jerry and Nancy Campbell, *Loudon, TN*

A memorial fund has been established in the name of

Mr. Friederich Koenig

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

Daniel and Lucy Kmet
Uniontown, OH

Albert and Mary Gawlik
Tallmadge, OH

Homer Heiser
Tallmadge, OH

Anton and Anna Putra
Lady Lake, FL

Ed and Kathy Miller
Fort Mill, SC

Joseph and Mary Recktenwald
Uniontown, OH

Fred and Karen Viall
Tallmadge, OH

Alfred Sander
Kent, OH

Waxman Consumer Group
Bedford Heights, OH

Bill and Debbie Mosholde
Tallmadge, OH

Doris Bovard
Tallmadge, OH

Larry and Vicki Fordham
Akron, OH

William and Cindy Volk
Akron, OH

Hans and Brigitte Leitner
Wadsworth, OH

Randy Lipscomb
Akron, OH

Laddie Davis
Barberton, OH

Eunice and Gerard Stein
Akron, OH

Joe and Cindy Halleck
Tallmadge, OH

Diane Taylor
Fort Lauderdale, FL

Olaf Sander
Lyons, CO

A memorial fund has been established in the name of

Mr. Joseph Kotelnicki

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

Alice Paul House
Indiana, PA

Trish and Jerry Elgin
Kittanning, PA

Kimberlee Cunkelman
Indiana, PA

A memorial fund has been established in the name of

Rev. Lawrence Larsen, Jr.

Donations have been made in Rev. Larsen's memory by:

Curt and Liz Eaton, *Olympia, WA*

A memorial fund has been established in the name of

Mr. Dotson Morgan

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

Scott and Ann Seely, *Edmond, OK*

A memorial fund has been established in the name of

Mr. Leroy W. Novak

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

Donald and Barbara Peterson
Park Ridge, IL

Frank Andrew Nibouar
Chicago, IL

Accelerated Receivables Management
Park Ridge, IL

John and Josephine Smolenski
Park Ridge, IL

Gwen and Robert Linder
Davis, IL

The Abington of Glenview
Glenview, IL

Dennis Beauchamp
and Rick Volden, *Chicago, IL*

Brenda Logan
Willow Springs, IL

Maria Eliesiu
Skokie, IL

Lorraine E. Perlini
Prospect Hts, IL

Kathryn Mueller
Chicago, IL

Don and Rhonda L. Mann
Tulsa, OK

Dr. Tom Luker and Tom Luker II
Tulsa, OK

Nancy Marston
Arlington Heights, IL

Robert and Suzanne Colbert
Arlington Heights, IL

Carol Fender-Ramirez
Palatine, IL

Stephen Chrapla
Park Ridge, IL

Marilyn Novak
Park Ridge, IL

A memorial fund has been established in the name of

Mr. Thomas L. O'Mealy

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

Sherry A. O'Mealy, *Montoursville, PA*

A memorial fund has been established in the name of

Mr. Harlan Peterson

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

Eloise Klitz
Ridgewood, NJ

Arthur and Susan Maroney
Ridgewood, NJ

Nancy, Lynn and Sarah McKenzie
Dobbs Ferry, NY

Thomas and Adrienne Donohue
Ridgewood, NJ

William and Gloria Monks
Hamilton Square, NJ

Jerry and Jill Mathe
Ridgewood, NJ

Peter and Sharon Coppola
Spring Lake, NJ

Conrad and Rosalie Daniels,
Hamilton Square, NJ

Phyllis Mahony
Wyckoff, NJ

Nancy Whittemore
Ridgewood, NJ

Howard and June Johnson
Nyack, NY

Stanley and Susan Dudek
Galveston, TX

Jacob and Joanne Smith
Glen Rock, NJ

Richard Varian
Brooklyn, NY

Leonard and Peggy Kirkuff
Hamilton Square, NJ

Ann and Lee Smith
Slingerlands, NY

John and Heather Witherspoon
Hilton Head, SC

Beatrice Eisele
Waldwick, NJ

Lawrence Kelly
Paramus, NJ

Judith and Richard Peterson
Redmond, WA

Frank and Karen Sheehy
Ridgewood, NJ

A memorial fund has been established in the name of

Ms. Dorothy Petta

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

Joyce and Lu Ann Kryder
Freeport, IL

APWU 05/86, Freeport Local No. 117
Freeport, IL

Lila and Leslie Bruce
Freeport, IL

Margot and Gus Petrakis
Freeport, IL

Theodore Bach
Freeport, IL

Ronald Beam
Cedarville, IL

Mr. and Mrs. Gerald Bender, Sr.
Freeport, IL

Larry and Suzanne Boyer
Freeport, IL

Mary Broderick
Minneapolis, MN

Stan Brubaker and Shirley Havens
Freeport, IL

Helen and Carole Busjahn
Freeport, IL

Tom and Teresa Casiana
Winneconne, WI

D.E. and J.A. Cook
Forreston, IL

Sally and Craig Cuplin
Freeport, IL

Pat and Gary Cuplin
Freeport, IL

Ruth Cuplin
Freeport, IL

Kathy and Gary Davis
Williamston, MI

Mary and Malcom Davis
Polo, IL

Chris Dewey
Chetek, WI

Ed and Betty Dillman
Naperville, IL

R.J. Drucker Enterprises
Freeport, IL

Joanne and Donald Engle
Freeport, IL

Patti and Alan Esker
Freeport, IL

Freeport Postal Employees
Freeport, IL

Jean Gilchrist
Freeport, IL

Eleanor Balles Grant
Arlington Heights, IL

Delia and Glenn Harman
Lena, IL

Mary Hartman
Freeport IL

Frank Henry
Freeport, IL

Sheila Hooper
Freeport, IL

Theresa and Randall Julius
Freeport, IL

Madeline Kleinhaus
Rockford, IL

Mary and Charles Koppi
Freeport, IL

Mary and Scott Larson
Freeport, IL

Nancy and Scott Larson
Freeport, IL

Robin and Dean Meinert
Rock City, IL

Karleen and Ervin Olson
Freeport, IL

Vicki and Frank Petta
Forreston, IL

Nancy and Bob Petta
Freeport, IL

Kristine Scheider
Freeport, IL

Elizabeth and Darwin Schroeder
Stockton, IL

Mildred Seefeldt
Freeport, IL

Ms. Dorothy Petta *(continued)*

Barbara Smith
Freeport, IL

Karen Spangler
Freeport, IL

P. A. Steele
Freeport, IL

Thomson Development Corporation
Savanna, IL

Norma and Don Valkem
Freeport, IL

Visible Changes / Roxanne Weik
Freeport, IL

Varick Warr
Freeport, IL

Mary and Warren Weber
St. Paul, MN

A memorial fund has been established in the name of

Mr. Jack Plauché

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

Atlantic Financial Group, LLC
Richmond, VA

Jerry and Teresa Burkhart
Belpre, OH

Karen Holub
Parkersburg, WV

19th Street Country Club
Parkersburg, WV

George Kellenberger
Parkersburg, WV

Michael and Drema Owens
Huntington, WV

Allison and Roger Plauché
Sedona, AZ

Elizabeth Lutz
Parkersburg, WV

Stephen and Darbie Higgs
Vienna, WV

Ben and Sylvia Garland
Vienna, WV

George Lantz
Parkersburg, WV

Jim Shriver
Parkersburg, WV

Ed and Mary Wagner
Port St. Lucie, FL

David and Sue Seldomridge
Dawsonville, GA

Richard and Elizabeth Adams
Parkersburg, WV

Thomas and Juliette Farson
Parkersburg, WV

Terry and Leslie Goudy
Parkersburg, WV

Jon and Mary Bango
Parkersburg, WV

Woody and Betsy Ehret
Parkersburg, WV

Carl and Cynthia Bullock
Vienna, WV

Jim Dowler
Parkersburg, WV

William Peters
Vienna, WV

Joyce Ancrile
Vienna, WV

Mike and Joy Durnell
Belpre, OH

Harry Esbenshade III
Vienna, WV

Jim and Mary Louise Deem
Parkersburg, WV

William Leachman
Parkersburg, WV

Tim and Vicky Hare
Vienna, WV

Jim and Becky McCutcheon
Parkersburg, WV

Dan and Debbie Rogers,
Parkersburg, WV

Vicki Heigel
Port Clinton, OH

Woody and Gloria Thacker
Coolville, OH

Dale and Helen Schuparra
San Antonio, TX

Craig Arnold
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