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Aplastic Anemia & MDS International Foundation

INSIDER

your resource for
answers
support &
hope.

AA&MDSIF to Bring
Patients & Families
Together With Experts
in More Cities in 2011

Conferences More Often and Closer to You!

AA&MDSIF is joining the best aspects of its annual Patient and Family Conference and the Living with MDS One-Day Conferences and Aplastic Anemia Updates into a new and expanded series: Living with Aplastic Anemia, MDS, or PNH. These regional conferences will occur in six cities around the country in 2011, and are designed to make more information on bone marrow failure diseases more accessible to more people.

Now patients will have the opportunity to attend a conference within just a few months of their diagnosis. The one day format will make it easier for family members to attend at a time that's convenient to school and work schedules.

2011 locations are

- Phoenix, AZ (March 26)
- Boston, MA (May 14)
- Cleveland, OH (June 11)
- San Francisco, CA (July 23)
- Minneapolis, MN (September 24)
- Tampa, FL (October 22)

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Standing Up For Your Health – A New Patient Self-Advocacy Program from AA&MDSIF

"You have to be you own best advocate. No one is going to take better care of you than you." Stephen King, PNH Patient

Knowledge is power, right? You've heard that saying many times. But is it really true? The truth is that knowledge is only potential power. Knowledge only gives you power when you use it to change your actions for your benefit.

Standing Up For Your Health, a new patient self-advocacy program being rolled out over the next few months by AA&MDSIF, is about knowledge and power. It is about learning what effective self-advocates do to make sure they get their best care and treatment and then doing those things yourself. It is both a mindset and a set of skills you can learn.

As we developed the *Standing Up For Your Health* program, our goal was to discover and share what powerful patients and effective self-advocates do that lead them to consistently receive quality care. We began by looking at what the research said about effective self-advocacy skills. Then we interviewed bone marrow failure disease patients, caregivers and healthcare providers to make sure we understood what self-advocacy skills were necessary for patients. Finally, we pooled what we had learned into teachable blocks—the five pillars of *Standing Up for Your Health*.

Self-Advocacy is the Means, Quality Care is the Goal

One of the main goals of this program is to provide you with tools and strategies to make sure you receive quality care. But what is quality care? If you search the Internet, there are lots of definitions. Quality care is described as care that fits your needs and preferences. It is care that is right for your illness. It is care that is given without unnecessary delays. It is care that does no harm.

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ABOUT US

Fighting Bone Marrow Failure Diseases Through Patient Support and Research Since 1983

MISSION

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) is an independent nonprofit organization whose mission is to support patients, families, and caregivers coping with aplastic anemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal hemoglobinuria (PNH), and related bone marrow failure diseases.

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Where Will We See You in 2011?

When Willie Sutton was asked why he robbed banks, he is reported to have said, "Because that's where the money is." So where are the patients we are working to serve? They are in all the obvious places. They are in their doctor's offices, on the Internet and spread all across the country. That's why we are making some significant changes in how we reach out to you and to those we haven't yet served.



This year, we will be providing more information to more physicians' offices so that when patients are newly diagnosed, it will be easier for doctors and nurses to share our materials and help connect patients and families to the full array of services we provide. You probably recall that day when you or a loved one were first told you had a bone marrow failure disease and didn't know where to turn. By "being there" for you and others in your doctor's office with the latest and best information, we hope to start serving you from that critical first day. You shouldn't have to wait to find us.

Where else will we serve you? Very soon, we will be launching a completely new Web site with additional features that will make it easier to find, access and share the latest educational, support, research and advocacy information. We are very excited about how we will be able to link our educational materials along with our Online Learning Center, Peer Support Network, advocacy and news items in a very user-friendly way. Watch for the announcements about the new AAMDS.org.

Perhaps the most significant change in reaching out to serve you where you are is in our patient and family conference program. For many years, our national conference brought together many of the world's leading experts to share the latest information about bone marrow failure diseases, new treatments and research findings. The 250 or so participants also had the opportunity to meet other patients and families, learn skills for living well and draw support from one another. But that only happened once a year. Also, the rigors and costs of travel, often across country, were a significant burden for many. In 2009, and 2010, we added a series of one day conferences particularly for MDS patients and families along with a short update program on aplastic anemia at the end of the day. These one day events enabled us to reach another 300 people, closer to their homes, with less cost and fewer travel hassles. They have been a huge success.

So for 2011, we are going to expand the one day format to include programs on three distinct tracks for aplastic anemia, MDS and PNH much like the national conference format has been. We will have many of the same experts as in the past, bringing the latest in research and treatment options, new sessions on living well, lots of time for your questions and plenty of opportunities to meet other patients and families. And we will be coming to six cities—Phoenix, Boston, Cleveland, San Francisco, Minneapolis and Tampa. As always, the conferences will be free, including meals and materials. We expect to serve more than 1,000 patients and family members with these six conferences this year and hope that you will be among them!

See the front page article in this *Insider* and be sure to catch the *eInsider* and our Web site for the latest news.

Stay well!

John M. Huber
Executive Director

Standing Up For Your Health (continued from cover)

During our 2010 patient and family conference, Dr. Carolyn Clancy, Director of the Agency for Health Research and Quality (AHRQ), provided a great definition of quality care: "Quality care is getting the right care at the right time delivered by the right healthcare professional for you." This is the definition of high quality care adopted for the Standing Up For Your Health program.

What Is Standing Up for Your Health?

This new program has been created entirely for your benefit. It is an integrated set of tools, learning experiences and materials for you to examine, evaluate, and engage with, with the goal of becoming a more effective advocate for your own healthcare.

How Can This Program Help You?

Standing Up for Your Health means you choose to become more knowledgeable about your health status and treatment options. You also choose to develop the skills needed to effectively communicate with medical professionals and medical institutions in a way that gets your questions answered to your satisfaction and assures your needs are met. You enhance your ability to act as a positive, proactive force, doing your part to ensure you receive the best care and treatment possible.

The *Standing Up for Your Health* program encourages and assists you in taking a more active role in your healthcare and provides you with the knowledge and practical strategies you can use right now to meet your new goal ~ quality care.

As this program rolls out, we will endeavor not only to educate, but to also engage you in discussions and activities. We will want to hear what works for you. And we will also be continuously sharing new information and insights that we learn and that have worked for others.

Five Pillars of Standing Up for Your Health

Our research showed that there is a set of activities and skills that powerful patients and strong self-advocates use. We call these the Five Pillars of *Standing Up for Your Health*. These are the core elements of this new program ~ essential skills to have if you are to receive your best care and treatment. The Five Pillars are:

1 Build a strong healthcare team. This team should include a specialist in your disease whom you are comfortable communicating with and trust. This gives you the best chance of being an active participant in your care.

2 Learn about your disease and treatment options. Although a diagnosis of bone marrow failure disease is an unwelcome life event, be curious and challenge yourself to know what is really happening in your body. Become familiar with treatment options and issues. Stay up-to-date on progress in the field. Learn the terminology used to describe your condition, your diagnosis, your treatment, and the potential outcomes. *Standing Up for Your Health* means you know where and how to find resources for help, including the many resources provided by AA&MDSIF.

- 3 Make the most of every office visit.** Be sure to prepare for each visit so you can get the most from the limited time you have with your doctor(s). Make a list of questions and prioritize them. Ask the most important questions first. And be sure you receive answers you understand. If you don't understand something, keep asking until you do understand.
- 4 Keep track of all health information.** This includes your health history, test results, and treatment information. Keep this information well-organized, easily accessible, and bring it with you to your office visits.
- 5 Build a strong personal support team.** Your team can be family members, friends, or professional caregivers. A support team helps you manage the tasks of daily life, provides emotional support, and assists you in understanding and tracking your health information. A support team also helps you in making the most of office visits by being sure all information discussed and answers given are captured.

How Can I Start My Self-Advocacy Journey?

The skills necessary to be a strong self-advocate and stand up for your health are easy to do. Start by picking one of the Five Pillars of the *Standing Up for Your Health* program (mentioned above), making a checklist of what steps are needed to be as prepared as you can be in that area and working on each step. Then move to another area. You will learn as you progress, but you will always be adding to your skill set in becoming an effective self-advocate.

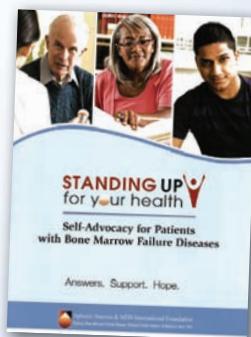
Where Can I Find More Information?

Be sure to visit our *Standing Up for Your Health* Web pages at www.AAMDS.org/StandingUp for more information about this new patient self-advocacy program. Here are some of the things you can do at this new section of AAMDS.org

- Complete a Self-Advocacy Skills Checklist.
- Read our *Standing Up for Your Health* Role Model story of the month.
- Review the Five Pillars of *Standing Up for Your Health*.
- View self-advocacy video presentations provided through our Online Learning Center.
- Share your stories of success with us!

New Patient Guide Available from AA&MDSIF

You can also order a copy of our new *Standing Up for Your Health* patient guide. It features much of the same content seen at www.AAMDS.org/StandingUp and is organized by the Five Pillars of Standing Up for Your Health. To get your copy, call (301) 279-7202 or (800) 747-2820, ext. 116 or email harper@aamds.org



AA&MDSIF 2010-2012 Research Studies Awarded

The Aplastic Anemia & MDS International Foundation is pleased to help researchers advance the understanding and treatment of aplastic anemia, myelodysplastic syndromes (MDS) and paroxysmal nocturnal hemoglobinuria (PNH). Each year, AA&MDSIF invites investigators to apply for two-year grants of \$30,000 per year to test new ideas and to explore other research leads. The applications are ranked according to merit by a distinguished panel of research scientists and funded by the generosity of families and patients.

Established and new investigators in bone marrow failure diseases can apply for these grants. Second-year funding is contingent upon progress in the first year.

Over the past 22 years, AA&MDSIF has provided nearly \$3 million in financial awards for research that leads to new insights into the causes and treatment of bone marrow failure and the development of new therapeutic approaches.

We are pleased to announce the recipients of AA&MDSIF 2010-2012 Research Grants:



Gregory A. Abel, MD
Dana-Farber Cancer Institute

• AA&MDSIF Research Grant including support from the Madden family in memory of Mary-Pat Madden Greishaber and the MacGillivray family in memory of Erwin Umbach

Developing a Disease-Specific Measure for Quality of Life in Patients with Myelodysplastic Syndrome (MDS)

Disease-specific quality of life measures allow better assessments of the impact of therapeutic interventions in both clinical and research settings; however, no such measures have been developed and widely adopted for the MDS patient population. Dr. Abel and his team aim to develop an MDS-specific quality of life instrument through focus groups with patients and providers and to further refine the instrument by piloting it with MDS patients.

For researchers, these efforts will establish a new instrument for potential use in multi-center treatment trials and health services studies to evaluate the potential effects of new treatments on MDS patients' quality of life.

For individual clinicians and patients, the instrument may also clarify issues to be considered in choosing management approaches. MDS patients may be able to use the process of completing the instrument to enhance their ability to address the areas which most concern them, and validate the importance of their voices in decision-making regarding their disease. Finally, health care planners and other

funding sources may also benefit from the information obtained with the new instrument to better understand the comparative effectiveness of management options.

"Little is known about the quality of life experienced by patients living with MDS, and how it might change with treatments. My hope is to create a standardized questionnaire that helps MDS providers and researchers more rigorously evaluate the quality of life of their patients. I was delighted to receive the AA&MDSIF award to develop such a questionnaire, particularly because the funding comes from a patient organization." - Gregory A. Abel, MD



Christian Bellodi, PhD
University of California
San Francisco

• AA&MDSIF Emily Kass Research Grant

p53 Translation Control in Hematopoietic Stem Cell Quiescence and Differentiation

Defects in the generation of ribosomes are present in many human syndromes, including X-linked Dyskeratosis Congenita (X-DC) and often underlie an increased susceptibility to hematological cancers. X-DC is invariably associated with mutations in the DKC1 gene, which encodes an enzyme that modifies ribosomes. During stress conditions, specific impairments in DKC1 alter the ability of the cells to produce important tumor suppressor proteins that are required to maintain cellular homeostasis. Dr. Bellodi's preliminary data suggest that transgenic animals lacking DKC1 (DKC1m) and human X-DC patient cells have a substantial defect in the synthesis of p53, a master tumor suppressor and key regulator of the hematopoietic stem cells' (HSCs) function.

Dr. Bellodi aims to understand how impairments in DKC1 alter HSCs' behavior and to what extent this defect contributes to bone marrow failure. The results may have broad implications for syndromes characterized by bone marrow failure due to impairments of ribosome function.

This proposal is directly relevant to the study of pediatric MDS, as X-DC patients have high risk to develop MDS. The mouse model of X-DC being used in this research lab has all the pathological features of X-DC including the MDS phenotype, and therefore is a relevant physiological tool for studying MDS in both pediatric and adult cases.

"This grant provides invaluable support as we work towards delineating the molecular basis by which deregulation in ribosomal function impairs the synthesis of key specific proteins, as well as understanding the extent to which this defect contributes to bone marrow failure. The results from this study will contribute to the identification of novel therapeutic strategies for their treatment." - Christian Bellodi, PhD



Muneoshi Futami, MD
Northwestern University
AA&MDSIF Harold Spielberg Research Grant

The Mechanism for Myelodysplasia in Patients with Loss of Chromosome 7

Loss of chromosome 7 (monosomy 7) occurs very frequently among adult and pediatric patients with myelodysplastic syndromes (MDS) or bone marrow failure syndromes that progress to myelodysplasia. Monosomy 7 carries with it a poor prognosis, even following a bone marrow transplant. Better understanding why monosomy 7 results in MDS would give rise to newer therapies, more effective and less toxic than bone marrow transplant. G-CSF stimulates the production of normal whole blood cells. Even though monosomy 7 is common, it is infrequent enough and difficult to culture monosomy 7 cells to study them.

Dr. Futami has developed two special cell lines that display abnormal proliferation and defective maturation that characterize MDS cells. He will use these two cell lines to identify the biochemical changes that make the monosomy MDS cells different from normal blood cells and will develop a mouse model to study the biochemical irregularities associated with monosomy 7.

"One important lead is that monosomy 7 cells express a defective receptor for the blood growth hormone G-CSF. By identifying the components of what makes a monosomy 7 blood cell diseased, we will be able to develop new types of therapies to correct them."

- Muneoshi Futami, MD

Web exclusive

Stories of Hope Survivor's Update



• Vincent Rogers of Storrs, Connecticut was profiled in the Spring 2004 issue of the AA&MDSIF Newsletter. Here, he reflects on his survivor's journey with humor, insight and optimism.

A maze of tubes connects me to mysterious devices that click, tick, and buzz. A group of perhaps ten residents and fellows sit quietly in a gallery opposite me.

All of the seats are full - a sellout.

Read all of Vincent Rogers' Story of Hope online at www.AAMDS.org/Hope



Ramon Tiu, MD
Cleveland Clinic
AA&MDSIF Torry Yahn Research Grant

LFA-3/CD2 Pathway: Potential Target for Immunosuppressive Therapy in Aplastic Anemia

The most effective drugs currently used as standard treatments (ATG, CsA) in aplastic anemia were developed and tested many years ago. However, the treatment results clearly should be further improved as not all patients respond to ATG. Many patients frequently experience return of their disease and treatment with ATG is toxic and may be dangerous. Dr. Tiu proposes to conduct a clinical trial of a new drug, Alefacept®. The advantage of this drug is that it is currently already available to patients with psoriasis, a chronic skin disease which in similarity to aplastic anemia is mediated by immune cells. While the diseased tissue is different in aplastic anemia, the basic disease mechanisms and thereby effects of Alefacept® may be similar. Dr. Tiu has designed a trial of this drug in patients with aplastic anemia in whom the traditional treatments did not work. This trial will determine whether Alefacept® is effective and well tolerated. Laboratory testing will be conducted to find out how it works and which patients may most benefit from it. Dr. Tiu believes that Alefacept® may prove helpful in aplastic anemia, and if this is the case, it can be quickly introduced into clinical practice as it is already available to patients with other diseases.

"Aplastic anemia is a rare bone marrow disease and unfortunately, the treatment options for this orphan disorder remain limited. We continue to use the decades-old drugs ATG and CsA, which are only effective in some patients. I am looking at the utility of a drug called Alefacept® for patients with relapsed and persistent aplastic anemia. If Alefacept® works, it could possibly become a new therapeutic option for patients." - Ramon Tiu, MD

HELP BUILD COMMUNITIES OF HOPE



In conjunction with the Living With Aplastic Anemia, MDS or PNH regional conference series, AA&MDSIF will be starting the Communities of Hope project. These are volunteer-led groups in each conference location (as well as other geographic areas of the country) to create an ongoing local network of patients and families, and help raise awareness and support for AA&MDSIF programs. Volunteers are needed to help organize these groups by working with AA&MDSIF staff and local professional resources.



If you are interested, contact Martha Crews at crews@aamds.org or (301) 279-7202 x103.

2008-2010 Research Grants Are Completed

All four of the two-year research grants awarded by AA&MDSIF in 2008 have been successfully concluded with final reports submitted.

"This most recently concluded group of research studies funded by AA&MDSIF has made a real contribution to further the understanding of genetic and biochemical actions that may enable bone-marrow failure diseases," said John Huber, AA&MDSIF Executive Director. "We are very appreciative of the efforts made by Dr. Braun, Dr. Minter, Dr. Maciejewski, and Dr. Risitano to contributing to the research side of our commitment to working towards a cure."

Research Grant Summaries



**Benjamin S. Braun, MD, PhD,
University of California,
San Francisco**

• AA&MDSIF Harold Spielberg
Research Grant

Mechanisms and Therapy of Anemia Caused by Activating Kras Mutation

We wanted to understand which cells in the bone marrow were responsible for anemia in MDS/MPN, and at this point, we suspect that mutations in the RAS family of genes are directing immature bone marrow cells to choose becoming white blood cells over red blood cells. To find out if a particular drug could help reduce this disease, we used a drug that blocked an enzyme called MEK, one of RAS's many collaborators in a cell. Mice treated with this drug showed a remarkable improvement, both in terms of reducing their white blood cell counts and improving their anemia.



**Jaroslaw P. Maciejewski, MD,
PhD, Cleveland Clinic Taussig
Cancer Center**

• Thanks to the generosity of
several major donors

Identification of Mutations in cCBL as Pathogenetic Factors in Patients with MDS

Single nucleotide polymorphism arrays (SNP-A) were used as an investigative tool to identify previously unknown chromosomal changes, including somatic uniparental disomy, in patients with MDS and related diseases. We have created cell lines which contain the mutations identified in patients and are currently using these cells to study the effect of drugs on the signaling pathways that are affected by cCBL mutations.



Lisa M. Minter, PhD, University of Massachusetts, Amherst

• AA&MDSIF Torry Yahn
Research Grant

Evaluating PKC-theta as a Therapeutic Target in a Mouse Model of Severe Acquired Aplastic Anemia

The Notch protein, known to be involved in aplastic anemia, also interacts with another protein, PKC-theta. Experimentation showed that transferring cells without PKC-theta into animals caused no signs of bone marrow failure and that blocking activity of PKC-theta decreases the activity of Notch. Furthermore, blocking the activity of Notch reduced the expression of PKC-theta and also prevented PKC-theta from being recruited into a bigger complex of proteins that is important in activating immune cells. Study results suggest that PKC-theta may be a novel target in the treatment of patients with aplastic anemia.



**Antonio Risitano, PhD,
University of Naples**

• PNH Research and Support
Foundation Research Study

Genetic Fingerprint of Complement and Complement-Related Genes in PNH: Relationship with Pathophysiology, Clinical Manifestations and Response to Eculizumab

We demonstrated that a recombinant human fusion protein called TT30 was able to completely prevent hemolysis of PNH red cells, also preventing the early complement activation on their surface. These data hopefully will represent a robust background for a clinical translation on this novel agent, aiming to a continuous improvement of clinical care of PNH patients.

Donate a *Gift of Hope* to AA&MDSIF

2011

Patient Education & Support Campaign



"Now it's time for me to pay it forward and help newly diagnosed patients the way others helped me in my time of need."

- Neil, patient

Give by mail, online or by phone at
www.AAMDS.org/DonateNow, or phone (301) 279-7202 x105.



AA&MDSIF 2010 Scientific Symposium Patient Summary Now Available

Learn about the most promising bone marrow failure disease research now underway and the best directions for the future in the AA&MDSIF 2010 Bone Marrow Failure Disease Scientific Symposium Patient Summary, now available online and in print.



Held in March 2010, the AA&MDSIF 2010 Scientific Symposium brought together most of the world's experts on the biology and treatment of aplastic anemia, MDS, PNH and related disorders. While the live event was a rare opportunity for these researchers to explore emerging ideas in person, AA&MDSIF made sure that the first publication resulting from the symposium was a summary for patients so they, too, know the latest information.

The summary includes a review of every presentation, written in lay language, so that patients and others can gain a better understanding of what impact current research may have on bone marrow failure disease therapies and potential cures. It also provides explanations of common elements in bone marrow failure diseases, recent developments in transplant and non-transplant treatments, and the genetics of aplastic anemia, MDS and PNH. Definitions of key medical terms are included to help make the research easier to understand.

The AA&MDSIF 2010 Bone Marrow Failure Disease Scientific Symposium Patient Summary includes information on:

- Genetics and epidemiology of MDS
- Genetics/immunobiology of aplastic anemia & PNH
- Pathophysiology/molecular targets in MDS
- Non-Transplant Treatments for aplastic anemia & PNH
- Transplant treatments for aplastic anemia, MDS & PNH
- Non-transplant treatments for MDS

For nearly 30 years, AA&MDSIF has recognized the importance of research leading to new insights into the causes of bone marrow failure disease and the development of new therapeutic approaches. Our research grant program has awarded nearly \$3 million in funding to almost 50 researchers, and many of those grantees participated in the symposium. AA&MDSIF research grants have been made possible by the generous support of families and patients.



Download a free copy online at
www.AAMDS.org/symposiumsummary or
 email harper@aamds.org for a free print copy.



Request a free print copy by calling (301)279-7202 or
 (800)747-2820, extension 116.

Over 800 Attend AA&MDSIF Symposium at ASH 2010

AA&MDSIF, in partnership with the Cleveland Clinic Center for Continuing Education, co-sponsored "Myelodysplastic Syndromes: Actively Treating the Disease and Aggressively Supporting the Patient", a well-attended symposium presented at the 2010 American Society of Hematology (ASH) Annual Meeting. This is the third consecutive year that AA&MDSIF and Cleveland Clinic have joined together to sponsor a symposium related to MDS at the ASH annual meeting.



According to Mikkael Sekeres, MD, MS, Cleveland Clinic, Co-Chair of the AA&MDSIF Medical Advisory Board and Activity Director of the Symposium, the symposium presenters provided updated data on established therapies that supported their efficacy and did not raise any additional safety concerns. The faculty also addressed how to better define subtypes of MDS based on molecular characteristics.

Asked why there was such a strong interest in the symposium topic, Dr. Sekeres said, "I think that, internationally, hematologists are seeing more and more MDS and are struggling with optimizing therapies based on the heterogeneity of the disease."



In addition to Dr. Sekeres, several AA&MDSIF Medical Advisory Board members also presented at the symposium, including: Aristotles Giagounidis, MD, of St. Johannes Hospital, Germany; Jaroslaw Maciejewski, MD, PhD, of Cleveland Clinic; Gail Roboz, MD, of New York Presbyterian Hospital; and David Steensma, MD, FACP, of Dana-Farber Cancer Institute.

The American Society of Hematology Annual Meeting is a forum for nearly 20,000 hematologists, oncologists and allied professionals from around the world to present and learn the latest research in hematology.

Patient & Professional Education

Research Update on MDS Diagnosis and Treatment Now Available in Multiple Formats

Each December, nearly 20,000 hematologists and oncologists gather for the annual meeting of the American Society of Hematology (ASH) to share their discoveries and learn about the most current research, new treatments, and better ways to use existing treatments.

In January, AA&MDSIF produced two webinars with the latest information reported at ASH on MDS:

- “New Strategies for Diagnosing and Classifying MDS: Can This Change Treatment Outcomes?” presented by David Steensma, MD, FACP, and Gail Roboz, MD. This webinar addresses new and emerging diagnostic procedures and prognostic models and how these tools might allow doctors to refine and tailor treatments to each specific MDS patient’s needs.
- “Emerging Treatments and New Protocols for MDS Therapy”, presented by David Steensma, MD, FACP, and Mikkael Sekeres, MD, MS. This webinar focuses on understanding new treatments and new ways of giving existing treatments and how these might provide better outcomes for patients.

 These webinars are now posted on the AA&MDSIF Online Learning Center (www.AAMDS.org/Learn). In addition to the original audio presentation and accompanying slides, two written formats are now available:

- A transcript to read along with the program
- A summary of the ASH abstracts mentioned in the webinars, written in plain language and including definitions of medical terms

 Both written formats may be downloaded to read or print. If you prefer, you can request copies to be mailed to you by contacting harper@aamds.org or by calling (301) 279-7202, extension 116.



Join the AA&MDSIF *Guardians of Hope*

In addition to the gifts you give today and throughout your lifetime, taking the time to write AA&MDSIF into your will or to make any other planned/estate gift provides an enduring legacy of your personal interest and commitment to providing education, service and research for those facing bone marrow failure diseases.

Ask your attorney to include this paragraph, specified to your gift preferences, in your will:

I give, devise, and bequeath \$____ (amount) or ____% (percentage) to the Aplastic Anemia & MDS International Foundation (AA&MDSIF), 100 Park Avenue, Suite 108, Rockville,

AA&MDSIF Offers Online CME for Hematology/Oncology Professionals

The AA&MDSIF Online Learning Center (www.AAMDS.org/Learn) recently added the following CME programs:

Performance Improvement Strategies

Learn to implement guideline-approved processes of care for your patients with MDS and earn 20 complimentary AMA PRA Category 1 Credits TM. PI CME is important for professional development and may answer credentialing and reporting needs. Use your data to complete ABIM’s Self-Directed PIM and earn credit for ABIM Maintenance of Certification (MOC).

Faculty Chair: Mikkael A. Sekeres, MD, MS,
Cleveland Clinic Taussig Cancer Institute

Optimizing The Continuum of Care for Myelodysplastic Syndromes

This activity is designed to meet the educational needs of hematologist/oncologists, nurse practitioners, physician assistants, and other health care professionals involved in the management of patients with myelodysplastic syndromes.

Upon completion of this educational activity, practitioners should be able to select active therapies for IPSS Low-/Int-1-risk MDS based on disease and patient characteristics. In addition, practitioners should know what to expect from treatment with newer therapies, including expected response and the approach to manage toxicities.

Faculty: Mikkael A. Sekeres, MD, MS,
Cleveland Clinic Taussig Cancer Institute
David P. Steensma, MD, FACP,
Dana-Farber Cancer Institute
Steven L. Allen, MD, FACP,
Hofstra North Shore Monroeville Cancer Center

MD, 20850, a not-for-profit corporation for its charitable uses as directed by its Board of Directors.

Please let us know if you've included AA&MDSIF in your will or estate plan, and we'll be pleased to recognize you today in our Guardians of Hope Society with a special thank you.

 To discuss your interests, learn more about making a bequest or other gift, or how to designate your gift for specific use, please call our Development Director, Sandra Walter-Steinberg at (301) 279-7202 x104 or email at walter@aamds.org.

Be a Strong Member of Your Healthcare Team—What Doctors Are Saying

It's not always easy to speak up for yourself at doctor visits. You may worry about hurting your doctor's feelings or giving offense by asking questions or requesting more information.

On the contrary, the providers we spoke with say they like when patients are proactive and involved. They want patients to be well informed and share information freely. And they appreciate good questions.

"It's really important for patients to be strong advocates for themselves," says Dr. Isabel Schuermeyer, a psycho-oncologist at the Cleveland Clinic in Cleveland, Ohio. "Being in control can lead to better outcomes and better quality of life."

Choose providers with care.

The strength of your healthcare team is one of the keys to receiving good healthcare. So keep looking until you find the doctor who's right for you.

"Make sure your provider is a good fit," says Dr. Ruben Mesa, a hematologist/oncologist at the Mayo Clinic in Phoenix/Scottsdale, Arizona. "You should have a shared understanding of your disease and treatment and be able to communicate well together."

Ideally, one member of your healthcare team will be an expert who knows a lot about your disease. When choosing an expert, don't be afraid to ask tough questions that require a direct answer. "Say, 'How many people with this illness have you treated in the last year?'" suggests Dr. Schuermeyer.

Choosing a provider with care is all the more crucial when you have a chronic disease. "It's a relationship that can last for years," says Dr. Mesa.

Prepare for every visit.

Doctors are busier than ever these days. Your visit may last just a few minutes. So make the most of the time you have by being fully prepared.

"I'd love to have two hours with every patient to go through every detail and contingency," says Dr. David Steensma, a hematologist/oncologist at the Dana-Farber Cancer Institute in Boston, Massachusetts. "But the clock is always ticking, and there is so much we need to discuss and accomplish in such a short time."

Start by learning all you can about your disease and treatment options.

"If you have a rare disease, it's important to be well informed even before you visit the doctor, so you know the right questions to ask," says Dr. Mikael Sekeres, a hematologist/oncologist at the Cleveland Clinic in Cleveland, Ohio.

Just make sure the information you're receiving is reliable, and don't trust poorly sourced information seen online.

"There's a lot of information out there on the Internet that just isn't accurate. You want to know your source," says Dr. Schuermeyer. "For example, I have patients who go into chat rooms and hear a lot of misinformation that is simply not true."

To get ready for each visit, set a goal. Ask yourself, "What do I want to get out of this visit?"

Bring to every visit:

- A list of questions in priority order
- A log of blood counts and transfusions
- An updated list of medicines, vitamins, and supplements you take
- Notes on symptoms and side effects

This may sound like a lot of effort. But this preparation will save you time when it counts most—during your office visits. Consider asking family or friends to go to the visit with you. They can help you ask questions, listen to answers, or take notes. They can also provide moral support.

Ask questions. Get answers.

Clear communication is another key to good healthcare. You have the right to fully understand your disease and treatment options.

"If something doesn't make sense, you need to speak up," says Dr. Steensma. "Mistakes happen. You shouldn't be afraid to ask questions."

Worried about offending your doctor? Don't be.

"If the doctor gets offended by lots of questions, it's probably the wrong doctor," says Dr. Sekeres. "They may not know enough."

Treat your providers with respect.

While it's important to speak up for yourself, be sure to treat your providers with respect. Remember that they are people too.

"When you disagree with someone, don't put blame on the person," says Dr. Schuermeyer. "Use 'I' statements. Say, 'I don't understand ...' or 'I'm concerned about ...'" "Patients need to realize that their doctor is their partner," says Dr. Steensma. "You need to think of your doctor as an ally instead of as an antagonist."

But keep in mind—it's your right to get a second, third, or even fourth opinion. In fact, most doctors like patients to get a second opinion.

So stand up for your health!

Remember: When you're a strong self-advocate, your doctor can do a better job of helping you stay well. And that's good for you—and your health.

AA&MDSIF to Bring Patients & Families Together (continued from cover)

New Conference Series Continues to Provide Answers, Support and Hope

A learning and networking-filled day for every attendee!

Get answers to your medical questions

- Three concurrent tracks for aplastic anemia, myelodysplastic syndromes (MDS) and paroxysmal nocturnal hemoglobinuria (PNH) will provide the most up-to-date thinking on disease, diagnosis and treatment options for each. This will be followed by presentations on new and emerging therapies. Attendees will have access to leading bone marrow failure disease experts addressing important aspects of each disease, from advances in treatment to strategies for living well with and beyond each disease. There will be plenty of time for your questions to be answered.



Learn about topics related to living well with aplastic anemia, MDS and PNH

- The afternoon will include a series of Living Well sessions on topics you have told us that you want to learn more about. Topics covered will vary by location, but may include managing fatigue, complementary and alternative medicine, nutrition and exercise, coping skills for maintaining emotional health, and survivorship.
- An increasing number of Vietnam era veterans are being diagnosed with MDS. Veterans and Bone Marrow Failure Diseases: A Discussion and Workshop will help them and their physicians in preparing appropriate disability claims.

Find support

- An interactive lunch program will encourage patients, families, and caregivers to meet each other, share ideas and experiences, and break down the sense of isolation often felt by those whose lives are impacted by these rare diseases. During this special lunch program, the emphasis will be on self-advocacy ~ sharing ideas on how to stand up for your health to receive the best care and treatment available.

Find Hope

- The day concludes with a Survivors Celebration. Join us for this celebration of life along with others who have survived the disease, undergone treatment and are creating a 'new normal' for a life beyond bone marrow failure disease! You will leave on a hopeful note, feeling confident, empowered, and inspired to be a strong advocate for your health care. You will also be better connected to other patients and their families.

If you've never attended one of our conferences, you won't want to miss this informative and inspirational event. If you have attended one of our conferences, join us again in this all-new format to learn more about advances in treatment, discover new strategies for living well with bone marrow failure diseases, reconnect with friends, and participate in our special Survivors Celebration.

For Younger Patients and Their Parents

For Kids Only – A Children's Workshop (San Francisco only)

This lively and interactive workshop is for children and teens ages 6 to 16 who have a bone marrow failure disease or who have siblings or parents with aplastic anemia, MDS or PNH. The For Kids Only workshop will include a mix of fun, facts, and even some medical science. David Margolis, MD (Dr. Dave), a pediatric hematologist, will spend time with the kids answering all their questions. Participants enjoy making new friends their own age, and they often stay connected with them throughout the year. The workshop ends with a fun ice cream social.



Pediatric Issues: An Intimate Q&A for Parents of Pediatric Patients (Boston, San Francisco, Minneapolis)

This open-ended question and answer session is designed specifically for parents of children with bone marrow failure diseases. Topics typically include bone marrow transplantation, intensive immune suppression, unmatched donor transplants and decision-making regarding when and when not to transplant. Bring your questions to the session to stimulate discussion.

Why Should You Attend One of Our Conferences?

- Hear from leading experts.** Learn more about your diseases, current treatments and emerging therapies.
- Explore a variety of topics** on living well and improving your quality of life.
- Get your questions answered.** Plenty of time will be provided in every session.
- Learn skills and strategies** that can help you stand up for your best medical care and become a more powerful patient.
- Meet other patients and family members** and get connected to a support network.
- Participate in our Survivors Celebration** and leave with a sense of hope and a positive outlook for the future.
- Understand how AA&MDSIF can help** you through this life-changing experience.
- Like any AA&MDSIF live event,** registration will be free and includes meals and all materials. However, advance registration is required. For more information, and to register, visit www.AAMDS.org/Conferences.

Patient and Family Conference attendees describe their experience

"My son and I are now filled with hope for his future. Thank you so much for all your hard efforts in putting forth this most informative and hope filled conference."

"I found the conference extraordinarily informative and helpful, and afterward felt like I had a pretty concrete grasp on what my current treatment options are, I really appreciate all the AAMDSIF does, and all the hard work they, the volunteers, and the speakers put into this."

"I was impressed with all of the volunteers and staff. Everyone was helpful and knowledgeable. My day was jam packed with opportunities for learning. This conference helped me realize that there are other people out there. Thank you so much for the hard work and effort put into this conference. It was great!"

"Wonderful experience for us as a family. The kids' workshop was excellent. The uplifting conference theme of surviving gave my husband hope for the possibility of many future years."

THE NEW AND IMPROVED AA&MDSIF MARKETPLACE IS OPEN FOR BUSINESS!

Show your AA&MDSIF spirit – and help spread awareness – with our practical and stylish Marketplace items!

New items are now available through our online Marketplace and our popular Bravery bracelets are still available. By purchasing Marketplace items, your support helps raise awareness and also helps fund the patient education, research, awareness and advocacy programs of AA&MDSIF.

Men's and Women's Red Polo Shirts (\$30 per shirt)

Classic short sleeve shirt with AA&MDSIF in white stitching and the Answers, Support and Hope logo in black stitching.

Sizes: Men's Sizes: M-XXL
Women's Sizes: S-XL



3 WAYS TO ORDER:

- ONLINE** at www.AAMDS.org/Marketplace
- BY PHONE** with credit card at (800) 747-2820 ext.105
- BY MAIL** with check enclosed – AA&MDSIF,
100 Park Ave., Suite 108, Rockville, MD, 20850

Canvas Tote bags (\$30 per bag)

Large boat-tote in natural with red straps and embroidered logo.



Canvas Hats (\$20 per hat)

Six paneled hat with adjustable strap in natural with Answers, Support & Hope logo embroidered on the front and www.AAMDS.org stitched on the back.



Shipping for the above items (shirts, totes, hats) 1 item: \$6.00, 2-3 items: \$12.00, 4 or more items, \$15.00

Bravery bracelets

(\$10 for 10 bracelets/1 pack)

Red and white silicone bracelets, symbolic of red and white blood cells.



Free shipping for up to 50 bracelets/5 packs. For orders of 6 packs or more, call AA&MDSIF (800-747-2820).

Visit the AA&MDSIF Online Learning Center at www.AAMDS.org/Learn

Launched in 2008, the Online Learning Center (OLC) is a comprehensive patient education portal housing more than 60 different multi-media learning opportunities. These include video presentations and interviews with many of the nation's leading bone marrow failure disease experts, along with live webinars (web seminars) and unique interactive learning modules.

Created by AA&MDSIF expressly for patients and their families, caregivers and advocates, all OLC content is free and available to anyone with access to a computer and a high-speed Internet connection.



Searchable Content

Visitors to the Online Learning Center can search by subject or presenter name, or you can view all the content recorded at a specific conference or event. You can also view all of our archived webinars categorized by topic:

- Aplastic Anemia
- MDS
- PNH
- Stem Cell Transplantation
- Clinical Trials
- Supportive Care
- Living Well
- Pediatric Issues
- Insurance Coverage
- Self-Advocacy

Understanding the Different Formats

At AA&MDSIF, we understand that each person learns in a different way. Therefore, our Online Learning Center presentations are provided in varied formats. This provides you with the opportunity to try each one out and decide what works best for you. Here is a guide to help you understand each format:

Webinars

Webinar is short for “web seminar.” Webinars allow many participants in multiple locations to see and hear a live presentation as it happens. A webinar typically consists of a presenter, a moderator, and an online audience. The audience hears the voice of the presenter and moderator and sees the slide presentation, but they do not see the presenter on video. At the end of the presentation, members of the audience can ask questions which are typed in a Q&A chat window that is opened on the viewer’s computer monitor. The entire listening audience then hears the presenter’s response. The webinar, along with the Q&A, is then archived for future viewing.

Webcasts

Webcasts are pre-recorded presentations that were given in front of an audience at an AA&MDSIF live event. Here, viewers see a video of the presenter along with the accompanying slide presentation and the follow up questions from the audience.

Interviews with the Experts

These are pre-recorded video events in which an expert in a particular subject area is interviewed by another person who is off-camera. A list of the questions being asked is also visible on the viewer’s computer monitor. Unlike webinars and webcasts, these interviews are not accompanied by a slide presentation.

Interactive Learning Modules

Interactive modules are online learning tools. When you open an interactive module, you progress through a series of slides that have text and graphics with a spoken narration of the text shown on each slide. You can repeat a page, skip ahead to a new section of the interactive module or even return to an earlier page. Information is presented in an easy-to-understand format, using graphics, animation, and audio. Interactive modules also help you learn by quizzing you on the content you have just covered. Questions are asked throughout the program and provide immediate feedback on your response.

Read what others have to say about the AA&MDSIF Online Learning Center

The live and archived webcasts and interviews are an invaluable source of information about bone marrow failure diseases such as mine. Whenever I have questions, the Aplastic Anemia and MDS International Foundation is always my “go to” source for answers. Thank you so very much for the knowledge and support you provide.”

“I do not have MDS ~ my father does. I view these programs to have a better understanding of his disease. I am so thankful to the doctors who take the time to do these great programs.”

Upcoming Webinars – Register Now!

Treating Lower-Risk MDS in 2011: Applying the Most Current Clinical Research to Patient Care

Tuesday, March 29, 2011 • 3:30 PM Eastern
Presenter: Mikael Sekeres, MD, MS
Cleveland Clinic Taussig Cancer Institute

PNH Clinical Update for Patients: Important Findings from ASH 2010 Annual Meeting

April 14, 2011 • 3:00 PM Eastern
Presenter: Ilene Weitz, MD
University of Southern California School of Medicine

Representative Doris Matsui Reintroduces Bone Marrow Failure Disease Research and Treatment Act (H.R. 640)

On February 10, Representative Doris Matsui (D-CA) reintroduced the Bone Marrow Failure Disease Research and Treatment Act. The bill, which is very similar to the legislation introduced by Representative Matsui in 2009, has been designated H.R. 640 in the 112th Congress (2011-2012).

H.R. 640 increases the Federal Government's commitment to researching and treating aplastic anemia, MDS, PNH, and other acquired bone marrow failure diseases. The legislation directs the Department of Health and Human Services (HHS) to combat these diseases through a comprehensive strategy that includes:

- **A national bone marrow failure disease registry** so that researchers can combine their data in one place, yielding more effective research designs and better results;
- **Pilot studies through the Agency for Toxic Substances and Disease Registry** to determine which environmental factors cause people to acquire bone marrow failure diseases;
- **Minority-focused programs** to make information on treatment options and clinical trials available to minority communities, particularly Hispanic and Asian American communities;
- **Agency for Healthcare Research and Quality grants** to help improve diagnostic practices and quality of care for patients with bone marrow failure diseases.

Last year, the U.S. House of Representatives approved a similar, but modified version of the bill. Unfortunately, the Senate did not act on this legislation prior to its adjournment last December. However, Representative Matsui remains committed to moving this important legislation through Congress this year toward ultimate enactment into law!

Please contact your U.S. Representative today and ask them to co-sponsor H.R. 640.

You can write a letter, make a phone call or go to the Action Center on our Web site at [| | |
|--------------------------------|-------------------------------|
| Altmire, Jason \[PA-4\] | Hall, Ralph M. \[TX-4\] |
| Baldwin, Tammy \[WI-2\] | Hastings, Alcee L. \[FL-23\] |
| Barrow, John \[GA-12\] | Hinchey, Maurice D. \[NY-22\] |
| Bishop, Sanford D., Jr. \[GA-2\] | Hirono, Mazie K. \[HI-2\] |
| Bishop, Timothy H. \[NY-1\] | Holden, Tim \[PA-17\] |
| Bono Mack, Mary \[CA-45\] | Honda, Michael M. \[CA-15\] |
| Bordallo, Madeleine Z. \[Guam\] | King, Peter T. \[NY-3\] |
| Braley, Bruce L. \[IA-1\] | Latham, Tom \[IA-4\] |
| Burgess, Michael C. \[TX-26\] | Lewis, John \[GA-5\] |
| Butterfield, G. K. \[NC-1\] | Loebback, David \[IA-2\] |
| Carnahan, Russ \[MO-3\] | McCotter, Thaddeus G. \[MI-11\] |
| Chandler, Ben \[KY-6\] | McDermott, Jim \[WA-7\] |
| Christensen, Donna M. \[VI\] | McGovern, James P. \[MA-3\] |
| Clay, Wm. Lacy \[MO-1\] | Miller, Candice S. \[MI-10\] |
| Cleaver, Emanuel \[MO-5\] | Murphy, Christopher S. \[CT-5\] |
| Cohen, Steve \[TN-9\] | Neal, Richard E. \[MA-2\] |
| Conyers, John, Jr. \[MI-14\] | Norton, Eleanor Holmes \[DC\] |
| DeGette, Diana \[CO-1\] | Olver, John W. \[MA-1\] |
| Ellison, Keith \[MN-5\] | Pitts, Joseph R. \[PA-16\] |
| Emerson, Jo Ann \[MO-8\] | Platts, Todd Russell \[PA-19\] |
| Engel, Eliot L. \[NY-17\] | Schakowsky, Janice D. \[IL-9\] |
| Eshoo, Anna G. \[CA-14\] | Schwartz, Allyson Y. \[PA-13\] |
| Faleomavaega, Eni F.H. \[AS\] | Stark, Fortney Pete \[CA-13\] |
| Frank, Barney \[MA-4\] | Towns, Edolphus \[NY-10\] |
| Fudge, Marcia L. \[OH-11\] | Van Hollen, Chris \[MD-8\] |
| Gonzalez, Charles A. \[TX-20\] | Wolf, Frank R. \[VA-10\] |
| Green, Gene \[TX-29\] | |](http://www.AAMDS.org>Action. A list of co-sponsors from the 111th Congress is shown below. We need their support again so please be sure to urge them to support H.R. 640.</p>
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Stories of Hope Camilo J. Valencia-Sevilla Aplastic Anemia Survivor, Spring, Texas

I am 48 years old, married with three kids. I used to be a very healthy person, until two years ago, when I was diagnosed with severe aplastic anemia. After I got severely fatigued playing competitive tennis, had a little fever and a bruise on my right leg that my wife noticed, I went to an urgent care center. Two blood tests later, I was in the hospital.

Since then, I've been through horse ATG and cyclosporine, rabbit ALG+Prograf, many transfusions, and finally, a bone marrow transplant from an anonymous donor. Today, I can almost do 100% of the things I used to do before aplastic anemia and more. I work, play tennis, play golf, swim, go sailing... participate in all family activities, etc. I couldn't be happier!

I wanted to share my story with you because I am confident that things happen for a reason, and we should never think that we won't recuperate. To the contrary, new challenges make us stronger, and we will learn lessons that maybe we wouldn't learn in any other way.



Volunteer Vibe

Judith Wilhelmy and the Red Hat Society Raise Funds for AA&MDSIF

Have you ever thought about planning a fundraising and awareness event? Do you read about other AA&MDSIF events and wonder if it's something you could do? We're here to tell you that you can!



The key to a successful event is to plan an event around something that you know well! And that's exactly what Judith Wilhelmy has done the past several years, in honor of her brother Frederick who is currently battling MDS.

Judith is an active member of her Red Hat Society club, so she thought this would be a perfect way to raise money and awareness for bone marrow failure disease. The Red Hat Society is the largest international social organization for women, dedicated to making the world a better place for its members by actively promoting and supporting fun, friendship, freedom, fulfillment and fitness for each individual, as well as demonstrating the value and contributions of women to society at large.

For her events, all Judith had to do was gather Red Hat Society members from the area, plan a social event, and bring everyone together. As part of her event, she gave out information about bone marrow failure diseases so that others could learn about them. She also found local businesses to donate items for her raffle to raise money for AA&MDSIF.

Judith has been planning these events for four years. The 4th Annual Red Hat Getaway Weekend was held from November 19-21, 2010 in the Boston area. Each year, Judith organizes a fantastic weekend at a local resort and spa. The weekend of fun includes dinners, entertainment, music, raffles, games and a true Red Hat celebration! There's also time to explore the historic sites and other areas of interest during the weekend.

Judith has had so much fun with her annual getaway weekends, she thought it would be a great idea to plan something during Aplastic Anemia & MDS Awareness Week. So, in December 2009, she organized a "Red Hat Victorian Christmas Luncheon." At this event, the ladies of the Red Hat Society gathered to celebrate Christmas with a luncheon, raffle, door prizes and entertainment. Money raised from the raffles benefitted AA&MDSIF.

To date, Judith has raised over \$4,000 for AA&MDSIF bone marrow failure disease education and support programs. We congratulate Judith on her events, her volunteer spirit, and her fundraising accomplishments!

 You, too, can make a difference by combining your interest or hobby with a fundraising and awareness event. What type of event do you want organize? There's no "one size fits all" event. For more information about planning an event, **please contact Martha Crews at (301) 279-7202 ext. 103.**

Get Involved...Give Back! Help Raise Awareness For AA&MDSIF!

A few hours of your time can help educate more people about bone marrow failure diseases. Be an ambassador for AA&MDSIF.

- **Host an AA&MDSIF House Party.**

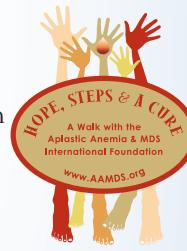
Just call or email family and friends. Tell your/your loved one's story about fighting a bone marrow failure disease and talk about how AA&MDSIF has helped you. Ask guests for a contribution to help.



Most of all, whether you throw a brunch, dessert party, happy hour or afternoon tea, have a great time as you raise awareness for AA&MDSIF. Remember, these can be small gatherings of 10 people or larger parties—you decide what works best for you. Ideas and tips are available at www.AAMDS.org/Awareness.

- **Organize a local walk.**

The Aplastic Anemia & MDS International Foundation's Hope, Steps & A Cure is a fun and festive walk in your own community to raise awareness about bone marrow failure diseases while raising much needed funds for AA&MDSIF programs and services to help patients and families.



- **Wear red to raise awareness.**

Order an AA&MDSIF hat or polo shirt to wear during the year to show your support. [See p. 11 for information about Marketplace]. Also order AA&MDSIF Bravery bracelets to give to family, friends and colleagues to wear in exchange for a donation.

 Want help contacting your local media? Need assistance with an idea? Want to reach other patients and family members through AA&MDSIF in your community? **Contact Martha Crews at crews@aamds.org.** Be sure to let us know what you did to support AA&MDSIF. Thank you in advance for your time and your commitment.



Patty Myers: A Survivor's Commitment to Advocacy

"I am an advocate 24/7 for AA&MDSIF and for anyone who needs information or just someone to talk to."

Patty Myers is a 57 year-old resident of Manheim, Pennsylvania, mother of a daughter who has recently graduated from Penn State—and a long-term MDS (myelodysplastic syndromes) survivor. Her participation in AA&MDSIF Capitol Hill Advocacy Day had a direct impact on obtaining the support of her Congressional representative for H.R. 1230, the Acquired Bone Marrow Failure Disease Research and Treatment Act. She speaks of her own experience with MDS, her advocacy and activism, and her hopes that other patients, families, and anyone whose life has been impacted by bone marrow failure disease will show their support by taking an active advocacy role.



Q: When were you first diagnosed with MDS?

I was diagnosed with MDS in 1993 during a routine annual physical. I am a nurse and one of the doctors I work with, after seeing my results, suggested I see a hematologist. The hematologist was unsure, but suggested MDS and described it as an "old person's disease". I was just 40 years old at the time of the diagnosis! The definitive diagnosis was made after bone marrow biopsy and a second opinion from the Hershey Medical Center.

Q: What was your reaction?

Shock was my first reaction to the diagnosis. My daughter was only 6 years old and I wanted to see my baby grow up. I wanted to see her attend the prom and go off to college, so my first thought was will I be here? I had no definite prognosis or time frame of life expectancy. There were other emotions of course – fear of dying and apprehension about side-effects of treatment therapies. I was given two years to live after failure of ATG therapy at NIH, but I beat the odds.

Q: How did you become involved with AA&MDSIF?

I was on the Internet in the midst of this turmoil, and after I was still alive for a few years, I found AA&MDSIF through a search engine. I thought "Oh my gosh, there are a lot of us out there!"

Q: What particular actions have you taken to support advocacy for MDS and other bone marrow failure diseases?

I decided I had to do something. I knew I could advocate for someone who could not, even if it was just a donation or passing out information. One small act could have an impact. I have

distributed AA&MDSIF literature at the Hershey Medical Center. I wish there had been a brochure for me when I was diagnosed, because I knew nothing. I have been to two Capitol Hill Advocacy Days. I was amazed to see how the system works. It gave me goose bumps to go to my Congressman's office (Joseph Pitts) and have the opportunity to speak for all of us.

Q: What do you feel finally got your representative to support H.R. 1230?

The reason he signed is because I was persistent and was better prepared at this second Advocacy Day. I recently spoke with Congressman Pitts. I thanked him for his support and co-sponsorship of the bill. He appreciated my advocacy for the group.

Q: What advice do you have for anyone who has been diagnosed with bone marrow failure diseases and anyone who wants to advocate for increased funding for research in fighting these diseases?

My advice to anyone who is diagnosed with this disease is to seek out information. Become familiar with www.AAMDS.org. Ask doctors for referrals. Be your own best advocate. If you don't understand, ask. And don't be afraid to ask for help. People truly want to help you, but be ready to identify the people who won't. I am living proof that you can live a long and quality life with MDS.

Also, help others as others have helped you. Volunteer. Be a friend and care. Try to stay up-to-date with what progress is being made in research and treatment, and this is where AA&MDSIF really helps—they bring information from the health professions to the patient's side. I am grateful for the effort being made by the medical community to find a cure and improved treatments for MDS.

Contact your legislator about supporting funding. At first, I thought "What will my visit or phone call really do?" Congressman Joseph Pitts from my district listened and signed on. Your voice has an impact and will be heard. I am still amazed how I made a difference. You can make a difference, too.

A Survivor Who Wants to Make a Difference for Others with MDS

Patty Myers has made a commitment to being an MDS patient who directs some of her time and resources towards being a part of the effort to help the cause. Her story makes it clear that there are opportunities for everyone whose life is impacted by bone marrow failure diseases to help be a part of the effort to find a cure, improve treatments and improve the quality of life for patients with MDS and other bone marrow failure diseases.

You can send a customized message urging support of H.R. 640 (the legislation introduced in the current session of Congress) by using our online advocacy tool at www.AAMDS.org>Action.



Aplastic Anemia & MDS International Foundation

100 Park Avenue, Suite 108 • Rockville, MD 20850
Phone: (301) 279-7202 or (800) 747-2820 • Fax: (301) 279-7205
Email: help@aamds.org • Web site: www.AAMDS.org

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Return this page with your comments,
email update@aamds.org or call
(301) 279-7202 x105.

Checklist for 2011

Learn More Inside and Online

- 2011 Patient & Family Conference Dates, Locations, Speakers and Registration Information, [www.AAMDS.org/Conferences](http://www.AAMDS.org-Conferences) [p.1]
- Read about our new *Standing Up for Your Health* initiative, [www.AAMDS.org/StandingUp](http://www.AAMDS.org-StandingUp) [p.1]
- Read about the 2010 Scientific Symposium Patient Summary, [www.AAMDS.org/symposiumsummary](http://www.AAMDS.org-symposiumsummary) [p.7]
- Visit the Online Learning Center to hear leading medical experts and register for the next webinar! March 29: Treating Lower-Risk MDS in 2011: Applying the Most Current Clinical Research to Patient Care [www.AAMDS.org/Learn](http://www.AAMDS.org-Learn) [p.12]
- Read about the Bone Marrow Failure Disease Research and Treatment Act reintroduced into the 112th Congress as H.R. 640, [www.AAMDS.org/Action](http://www.AAMDS.org-Action) [p.13]

Take Action

- Dedicate a day in honor or memory of a loved one or to celebrate your own life, on our 2011 Calendar of Hope. See enclosed envelope and [www.AAMDS.org/Dedication](http://www.AAMDS.org-Dedication).
- Help create a Community of Hope in your area. [Contact crews@aamds.org](mailto:crews@aamds.org) or call (301) 279-7202 x103 [p.5]
- Put AA&MDSIF in your will and become a Guardian of Hope. [Contact walter@aamds.org](mailto:walter@aamds.org) or call (301) 279-7202 x104 [p. 8]
- Give a Gift of Hope to AA&MDSIF, www.AAMDS.org/DonateNow [p.6]
- Raise Awareness – buy a shirt, hat, tote or bracelet at the AA&MDSIF Marketplace, [www.AAMDS.org/Marketplace](http://www.AAMDS.org-Marketplace) [p.11]
- Volunteer to hold a fundraising event in your community. [Contact crews@aamds.org](mailto:crews@aamds.org) or call (301) 279-7202 x103 [p.14]



ARE YOU ON THE AA&MDSIF EMAIL LIST?

- Email is the fastest and most cost-effective way for us to bring you important medical and health information and AA&MDSIF program news.
- Don't miss out on informative and inspirational news through our monthly *eInsider*, timely updates and special invitations during the year.

HOW TO GET IMPORTANT INFORMATION!

- If you have an email address, but don't receive messages from AA&MDSIF, please contact us with your email address, at update@aamds.org
- If you have stopped receiving our messages, please be sure that they are not blocked by your spam or junk mail filter.
- If you don't have an email address, free accounts are available at many sources, including Yahoo, Gmail, and MSN. When you set up an account, please let us know what your new email address is at update@aamds.org. Be assured that your email address will never be sold, rented or shared with any other organization or company.
- If you are unable to establish an email address for yourself, AA&MDSIF would like to stay in touch by sending our announcements to a family member, caregiver, or friend. It's important for them to be informed as well, and they can pass the information on to you.