Growth Factors and Medicare

On May 14, the Centers for Medicare and Medicaid Services (CMS) issued a “Proposed Coverage Decision Memorandum for the Use of Erythropoiesis Stimulating Agents (ESAs) in Cancer and Related Neoplastic Conditions.” CMS had examined its coverage policy after the Food and Drug Administration (FDA) issued a warning about the use of ESAs in kidney and cancer patients. The studies that caused the FDA concern did not appear to apply to bone marrow failure patients unless they also had kidney disease or a history of a solid-tumor cancer. Still CMS proposed to stop paying for ESAs for the treatment of MDS as well as other non-bone marrow failure conditions. (While many patients with bone marrow failure are treated with ESAs, by law Medicare is allowed to pay for ESAs only for MDS because the accepted published research pertains only to MDS. Hence the proposed decision memo and final decision affected only MDS patients.)

The AA&MDSIF firmly objected to this proposal on the grounds that scientific studies support the use of ESAs for patients with bone marrow failure. Concerned about access to ESAs for Medicare beneficiaries as well as for privately insured patients (whose insurers often follow CMS policy), we actively worked to reverse the CMS decision. The Foundation, in the name of its Medical Advisory Board, submitted strong comments on two separate occasions. The Foundation also went to the CMS headquarters to explain our objections to the CMS staff in more detail; we also met with many Congressional offices to outline our critique of the CMS proposal. Representatives John Tanner of Tennessee and Doris Matsui of California wrote a letter to Leslie Norwalk, the Acting Administrator of CMS, to express their concerns about CMS’s recent actions. Several other members of Congress—Representatives Richard Neal, Shelley Berkley, Jerry Weller, John Lewis, and Allyson Schwartz—also wrote to CMS at our urging. Many of you also wrote and called your representatives and senators in Washington to note your opposition to the CMS proposal.

CMS reviewed the many comments and on July 30 issued its final National Coverage Decision (NCD) regarding the use of ESAs in treating non-renal (or non-kidney) disease. In that decision, we were very pleased to see, CMS chose not to remove coverage of ESAs for MDS. It reversed its original proposal that Medicare beneficiaries with MDS could not receive ESAs.

There is one caveat to this good news in that CMS did not say that ESAs must be covered but said only that it was not removing coverage. The final policy allows “[l]ocal Medicare contractors…(to) continue to make reasonable and necessary determinations on all uses of ESAs that are not determined by National Coverage Determination (NCD),” including MDS. We will monitor local contractors’ policies closely, but to date no carrier has implemented a policy of not covering ESAs for MDS. If coverage is restricted in any region, the Foundation will mobilize its resources again. Hence Medicare policy coverage on ESAs for MDS now remains the same, and Medicare beneficiaries with MDS should have any ESA treatments covered by Medicare.

To all of you who wrote, faxed, emailed, and called your congressional representatives and submitted comments to CMS, thank you! We also want to thank the members of the House of Representatives and Senate who supported our efforts in convincing CMS that MDS patients need continued access to ESAs and the staff of CMS who listened to the medical evidence we presented.

(Please see sidebar, page 2)
If you or someone you know is battling bone marrow failure disease, clinical trials can be a valuable option. The National Institutes of Health’s Bone Marrow Failure Disease Consortium (BMFDC) is recruiting patients around the country for several new approaches to treating bone marrow failure. The Aplastic Anemia & MDS International Foundation, as part of the BMFDC, encourages you to consider a clinical trial and to see if you are eligible for one.

Behind every successful treatment option for a disease is a clinical trial—and the subjects who participated in that study. Clinical trials are research studies that look at how well a medication or a procedure will work in patients in the hope of finding a better way to treat diseases. Clinical trials may also compare how one treatment works in relation to another treatment.

Clinical trials are particularly important for rare diseases like aplastic anemia, MDS, and PNH and typically need many patients. (Different trials need different patients who have had different treatment histories; the study description will tell you what patients are eligible for the trial.) Trials have led to the approval of a number of effective drugs (like Dacogen®, Exjade®, Revlimid®, Soliris®, and Vidaza®) and procedures (like bone marrow transplants), but not all patients do well with the available treatment options. Clinical trials, while open to a number of people, can be of particular interest to such patients and may hold the key to success for them.

Currently several important clinical trials are being conducted across the country at well known hospitals by prominent researchers through the BMFDC established by the National Institutes of Health (NIH). Operating under the umbrella of the NIH’s Rare Diseases Clinical Research Network, the BMFDC is recruiting patients for several clinical trials to find better treatment options for patients. All the trials have been approved by experts in research to make sure that the study is designed well and that protections for patients are in place.

The BMFDC now has one clinical trial open for patients with aplastic anemia and two trials open for patients with MDS:

- **5403**: A Phase I/II Trial of Sirolimus (Rapamune®) and Cyclosporine in Patients with Refractory Aplastic Anemia
- **5405**: A Phase I Study of Revlimid® in Combination with Vidaza® in Patients with Advanced Myelodysplastic Syndrome (MDS)
- **5406**: Mechanism and Response of Thymoglobulin in Patients with Myelodysplastic Syndrome (MDS).

For more information about participating in one of the trials, visit [http://rarediseasesnetwork.epi.usf.edu/bmfdc/take-action/index.htm](http://rarediseasesnetwork.epi.usf.edu/bmfdc/take-action/index.htm), or contact Beth Bradley, AA&MDSIF Clinical Trials Educator, at 800.747.2820, 410.867.0242, or bradley@aamds.org.

If you are eligible for a trial but do not live close to the research site, the AA&MDSIF offers travel assistance to clinical trials. In addition, there are other resources that may assist you with any related travel costs.

These trials cannot succeed without patients. Thank you for your interest! 

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**If you have problems with Medicare coverage of growth factors**

If you are unable to receive your medication because of this policy change, please call our office, or email Christin Engelhardt, Director of Programs, at engelhardt@aamds.org. You can also take the following actions:
- If your doctor says that he/she cannot give you the growth factor because Medicare will not pay for it and if it is still medically appropriate for you to get the growth factor, ask your doctor to contact your regional carrier for Medicare to make sure that they understand your diagnosis. There is likely to be some confusion over coverage for MDS.
- If that step is not effective, you can call Amgen’s Reimbursement Hotline at 800.272.9376 or Ortho Biotech’s PROCRIT Line at 800.553.3851.

If your local Medicare carrier does change its policy, the Foundation would work again to see that ESAs are covered appropriately. In the meantime, if the local carrier’s policy prevents you from getting the medication your doctor prescribes, you can appeal any denial with help from the AA&MDSIF.
Bone Marrow Failure Disease Consortium Clinical Trials

Note: The study descriptions below are only summaries from the AA&MDSIF. For a complete description, visit http://rarediseasesnetwork.epi.usf.edu/bmfdc/takeaction/index.htm.

5403: A Phase I/II Trial of Sirolimus (Rapamune®) and Cyclosporine in Patients with Refractory Aplastic Anemia
This study will evaluate the safety and effectiveness of giving sirolimus in combination with cyclosporine to aplastic anemia patients. Patients with acquired moderate or severe aplastic anemia with bone marrow cellularity less than 25% who have not had a lasting response to at least one course of ATG and who have any of the pre-defined features at the time of the original diagnosis are eligible. Participants must be at least 21 years.

5405: A Phase I Study of Revlimid® in Combination with Vidaza® in Patients with Advanced Myelodysplastic Syndrome (MDS)
This is a study to determine the maximum tolerated dose (MTD) and dose-limiting toxicity (DLT) of combination therapy with Revlimid® and Vidaza® in patients with advanced MDS. The secondary purpose of this study is to review how well patients with advanced MDS do with this combination therapy of Revlimid® and Vidaza®. Up to 36 patients will be enrolled. Participants must be at least 18, have MDS with a life expectancy of more than 3 months, and have an Eastern Clinical Oncology Group (ECOG) status of 0, 1, or 2.

5406: Mechanism and Response of Thymoglobulin in Patients with Myelodysplastic Syndrome (MDS)
This is a study to estimate the overall clinical response rate to Thymoglobulin as therapy in patients diagnosed with MDS and to determine whether the presence of expanded T-cell clones can predict hematological response. This study is designed to recruit 14 patients per stratum in phase 1 and then increase to 27 per stratum if one person responds. The total number of patients will be from 28 - 54. Participants must be at least 18.

For more information about these studies, contact any of these study coordinators:

Cleveland Clinic Foundation
Susan Sunkle at 216.445.2119 or sunkles@ccf.org

Penn State Cancer Institute
Lynn Ruiz at 717.531.7377 or lruiz@psu.edu

University of California at Los Angeles
Meenal Chalukya at 310.825.8091 or mchalukya@mednet.ucla.edu

H. Lee Moffitt Cancer Center
Kara Kosakowski at 813.745.1706 or kara.kosakowski@moffitt.org or tera.uliano@moffitt.org #5406

Behind every successful treatment option for a disease is a clinical trial—and the subjects who participated in that study
In May 2007, the Aplastic Anemia & MDS International Foundation (AA&MDSIF) today announced the appointment of John M. Huber as its new Executive Director. John brings to the Foundation more than 37 years of leadership experience with associations, foundations and non-profit organizations.

“I am pleased to announce as our new Executive Director, a man with distinguished health care association and foundation leadership credentials,” stated Neil Horikoshi, the Chairman of the Board of the AA&MDSIF. “John Huber possesses the experience, expertise and managerial skills we need to meet a growing constituency of patients and families coping with bone marrow failure diseases. I am confident that John will be able to take the success that our Foundation has enjoyed to the next level.”

John joins the Foundation after serving as Executive Director of the American Urological Association Foundation (AUAF). Prior to serving with the AUAF, John served for eight years with Goodwill Industries International (GII), most recently as its Vice-President of Membership Support Services. He also served as the National Executive Director for the Lupus Foundation of America. During his tenure with these three organizations, Huber developed a track record of creating and implementing new governance models and strategies, securing financial resources for patient education and research programs, expanding membership, and deploying “member service” driven concepts.

“I am deeply honored to have this opportunity to serve the thousands of individuals worldwide who are suffering from bone marrow failure diseases,” stated Huber. “The Aplastic Anemia & MDS International Foundation is a tremendous advocate and resource for education, research, and emotional support for patients and families. I hope to expand and improve the reach of our Foundation to ensure that we doing everything we can to fight for a cure for bone marrow failure diseases and improve the lives of those affected.”

From the Executive Director

Our Opportunities

Hello!

This month I begin my 38th year of service in the nonprofit world. For the past six months of that time, I have been privileged to serve as your Executive Director. Thanks to so many of you who have made me feel so welcome.

Entering any new situation, it is important to learn the “5 P’s” – people, plans, programs, policies and politics – that are inherent in any organization. So while we were busy getting ready for the Patient and Family Conference and working to convince Medicare to continue funding a critical treatment for MDS patients, I also spent much time learning. Learning about bone marrow failure diseases; visiting with patients, parents, and family members; talking with physicians, researchers, donors, drug companies, members of Congress, board members and volunteers. Listening, always listening for what your needs are, what we can do better, what might be missing and what we can learn. It has been a busy summer.

When I was asked to consider this position, I asked “what is different about this Foundation, what is the opportunity?” In many ways the AA&MDSIF is like hundreds of other foundations and voluntary health organizations. We gather and disseminate patient information, provide a range of services, support research, engage in advocacy and raise money. Sure, some other organizations are bigger or smaller, have chapters, are better known or focus on only one service. That is a distinction without a difference. Every organization faces the challenge of what it is going to be or do and how it will do it. So, too, we face those questions. How are we different? How do we add value?
Some would say it is the quality, depth and range of information we have available. Others would suggest it is our patient support program that is the difference, with our patient information specialists, global support volunteer network and Marrowforums. I would suggest that it is our patient focus that is the real difference. It is the combination of information AND support, with patients as the focal point that distinguishes us from others. Why is this so important?

Much of my career has involved developing leaders at all levels. About ten years ago, Jim Collins wrote a book called “Built to Last” in which he notes that the most successful organizations and leaders are those who reject the “tyranny of the OR” and embrace the “genius of the AND”. What does this mean for us? It means that we don't just generate and publish information OR provide patient support by email or phone. It means having the latest, most accurate information available AND having talented, trained staff and volunteers to help patients understand the information.

It doesn’t mean funding research OR advocating for legislative change, but rather raising money to fund research AND petitioning government to direct more resources to finding the causes, cures and treatments for bone marrow failure diseases – more resources than we could ever raise.

It doesn’t mean seeking only private dollars OR relying on support from pharmaceutical companies but rather blending support from all those whose interests match ours – to benefit patients – AND operating in a completely ethical and transparent manner.

It’s not do we hire staff OR use volunteers to provide patient services, but rather it is having a network of physicians AND volunteers AND support group leaders AND professionals working together to meet the needs of those we serve.

You get the point.

So what, then, is the opportunity we have before us and how do we make it a reality? The opportunity is to build on the success of our past, a success rooted in a commitment to be patient-focused.

The opportunity is to adopt and adapt the best practices of the most successful non-profit and for-profit organizations, to a small, but dynamic organization which is poised for growth.

The opportunity is to incorporate the extraordinary potential of technology for communication, learning and sharing to complement and enhance the human patient focused touch that distinguishes our foundation from others.

The opportunity is to provide a full range of patient-focused services so that we become the resource of choice for patients, family members and caregivers.

The opportunity is to work in partnership with physicians, researchers and other health care professionals to bring the latest research findings and newest information to patients.

The opportunity is to explore and develop new linkages with other non-profits, businesses, foundations, drug companies and other corporate partners to conceive, design, fund and deliver new and innovative services – some that have not yet been dreamed of.

The opportunity is to promote the idea and deliver the message that bone marrow failure diseases and the people who live with them are no less worthy of focus, attention and support than any other disease, cause or campaign.

How do we view this opportunity?

A man walked up to a large construction site one day and saw three brick masons at work. He asked what they were doing. “Laying bricks,” said the first. “I’m putting up a wall,” said the second. The third mason said, “I’m building a cathedral.” Some organizations lay bricks. Others put up walls. That’s okay.

With the cornerstones of patient focus, innovative thinking, collaboration and commitment to success, how about we build a cathedral? With your help, I know we can.
Thanks to generous donors and passionate fundraisers, the Foundation has been able to award three two-year research awards for the 2007-2009 cycle. These are in addition to five other grants now in their second year. Each researcher receives a total of $60,000 from the AA&MDSIF to support his/her work which can lead to better outcomes in bone marrow failure treatment. The Foundation received nearly twenty applications from researchers around the world, and members of our volunteer Medical Advisory Board reviewed and scored each one. Funding allowed us to select three grants this year, two in MDS and one in aplastic anemia.

The project “Studies Toward Alternative Therapies for Iron Overload Patients with Aplastic Anemia” of Hiromi Gunshin, MD, PhD, at the University of Massachusetts Amherst, will be funded by the Ewert family. The Ewerts have been prolific fundraisers in memory of their daughter Trinity who sadly lost her battle against aplastic anemia.

Jim and Lois MacGillivray are supporting the research of Kay Macleod, PhD, of the Ben May Institute for Cancer Research University of Chicago. Dr. Macleod will be conducting research into “Oxidative Stress in the Etiology of Myelodyplasia” which is of particular interest to the MacGillivrays, given Jim’s diagnosis of aplastic anemia and then MDS. The grant is made in memory of Lois’s father, Erwin Umbach, who died of MDS.

Shizue Spielberg has donated to the research program for many years now in memory of her husband Harold who died in 1999 after living with MDS. Her generosity this year is enabling Lubomir Sokol, MD, PhD of the H. Lee Moffitt Cancer Center in Tampa, Florida to study “Microarray Profiling of Micro RNA in 5Q Minus Syndrome.”

If you are interested in sponsoring a research grant, please contact Executive Director John Huber, by calling the office or emailing him at huber@aamds.org.

In Praise of our Medical Advisory Board Chairs

The Aplastic Anemia & MDS International Foundation has long been guided by a volunteer Medical Advisory Board (MAB) composed of prominent experts in bone marrow failure diseases around the country. Chaired now by Richard Stone, MD of the Dana Farber Cancer Center and Harvard Medical School and co-chaired by Mikkael Sekeres, MD of the Cleveland Clinic, the MAB members provide input to the Foundation on the current science; offer opinions on developments in the field of bone marrow failure, including new drugs and procedures; review and score research applications each year; and advise the Foundation staff and Board of Directors on a variety of issues. Most recently, the Drs. Stone and Sekeres, pictured at left, have been invaluable to the AA&MDSIF as the Foundation addressed the issue of Medicare coverage of red-blood-cell growth factors or erythropoiesis-stimulating agents (ESAs) for MDS. Their prompt and thorough comments and suggestions are always extraordinarily helpful; their gifts of time to patients are beyond compare. The Foundation is truly fortunate to have them lead the MAB.
2007 AA&MDSIF Holiday Card Order Form

THREE WISE MEN: Front reads: “Peace on Earth” Inside verse: “To wish you the gift of faith, the blessings of hope, and the peace of his love at Christmas and always.” Gold foil lined envelope.

 FALLING SNOW: Front reads: “Greetings of the season” Inside verse: “A wish for a warm and wonderful holiday and a bright and beautiful New Year.” Translucent envelope.

HOLIDAY WREATH: Front reads: “Season’s Greetings”. Inside verse: “May the peace and joy of the holiday season be with you throughout the coming year.” Green deckle edge envelope.

PRETTY PACKAGE: Front reads: “Greetings tis the season of giving.” Inside verse: “Wishing you the most joyous holiday season and happiness in the New Year.” Gold foil lined envelope.


MINI TREE: Front reads: “Happy Holidays”. Inside verse: “Wishing you every happiness this holiday season and throughout the coming year.” Gold foil lined envelope.

ANGELIC BIRTH: Front reads: “For unto you a child is born.” Inside verse: “May you have the spirit of Christmas which is peace, the gladness of Christmas which is hope, the heart of Christmas which is love.” Silver foil lined envelope.

All cards carry this message: “A contribution has been made to the Aplastic Anemia & MDS International Foundation to fight aplastic anemia, myelodysplastic syndromes and PNH.”

Each selection contains 20 cards and 20 envelopes.

Return lower section with your check to:

Kathy Lancaster
2451 Roselawn Street
Wolverine Lake, MI 48390

PLEASE MAKE CHECK PAYABLE TO: AAFM

Shipping is already included in price. Allow 2 weeks for delivery.

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SUBTOTAL

Please accept my additional donation of...

TOTAL OF CHECK

NAME

ADDRESS

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STATE__ ZIP

PHONE ( )

EMAIL

I will accept a substitute if my selection is sold out.
I have numbered cards in order of my preference.

* Your personal info is for the purpose of this order only.

QUESTIONS? CALL (248) 624-1394
**Play Golf for Life**

On May 24, the First Annual Play Golf for Life Tournament was held in Richmond, VA. The event was planned and organized by Robby McKetta, a financial advisor for Merrill Lynch, in honor of his fiancé’s sister who lost her battle with aplastic anemia. Anyone who has ever organized or run a golf tournament knows the hundreds of details involved in such an event. From selecting a suitable course, recruiting golfers, soliciting sponsors, arranging meals and keeping fingers crossed for good weather, Robby did it all. This remarkable young man was responsible for making this initial event a rousing success with more than $31,000 raised to support the AA&MDSIF and the Massey Cancer Center at Virginia Commonwealth University. Thank you, Robby!

**Caring Car Cruise**

Thank you to the City of Jeanette Pennsylvania for your support of the 8th annual Caring Car Cruise in honor of Holly Cataldo. Holly’s Sister, Christina Beranek, and many friends, family, and volunteers, made this all happen and they have already funded one year of Dr. Ly’s research entitled “Telomere Maintenance in Patients with Aplastic Anemia”. Dr. Ly wrote an endearing letter to Holly’s family this month and has let us share it with you:

**Dear Mrs. Cataldo:**

It is wonderful to learn that the legacy of your daughter, Ms Holly Cataldo, lives on in Pittsburgh. I am deeply honored to be the direct beneficiary of the Holly Cataldo Memorial Research Fund. We pledge to do our very best at the bench (i.e., in the laboratory) to try to find a cure for AA & MDS. These are indeed formidable forms of bone-marrow failure syndromes.

I salute the Cataldo family and Holly’s friends and supporters who participate in the annual Caring Car Cruise event for doing their part to keep her memory alive. As a matter of fact, her photo is sitting on my desk in the office as a daily reminder of what we must strive to accomplish to help rid of these debilitating and sometime fatal diseases.

I would like to sincerely thank you and all of Holly Cataldo’s supporters for raising the fund that is enabling us to do the work that we hope will benefit all those who are either directly or indirectly affected by AA or MDS. I must apologize for not being able to help you with this important fund raising event. As the fall semester has just started here at Emory, I am scheduled to teach our incoming classes of graduate and medical students. Instead, I am sending to you a recent photo of our research team as a small token of appreciation for your continuing support of our research agendas.

With warmest and best regards,

Hinh

Christina Beranek received a plaque in recognition and thanks for her efforts. Thank you Christina for all you’ve done in Holly’s name!

**Catherine’s Craft Fair**

What an amazing girl! Sixteen-year-old Catherine Maclean was quoted at age 10 saying, “I hope I can make the world a better place for kids.” While sitting in the hospital recovering from her bone marrow transplant for aplastic anemia, Catherine spent endless hours making beautiful crafts such as necklaces, beaded hairpieces, and friendship dolls.

Today, she still holds her craft fair at her residence in Hamilton, Massachusetts, and she’s in her 7th year. It continues to be a success with the total amount raised to date being $4,635.

While Catherine still does most of the crafts herself, over the years she has enlisted the help of her friends and family and local businesses to contribute. In addition to Catherine’s crafts, there are also activities for children, such as carnival-like games, bean bag toss, and hitting a ball into a hole, all of which Catherine herself crafted.

This year’s craft fair also included the high school Jazz Combo and a high school rock band, “Distant Sun”. Catherine said, “We had big crowds, great music, food, crafts, and lots of fun. I enjoyed myself a lot, and the volunteers and bands that came said they had fun too.” Catherine raised twice as much this year as the year before and said, “I’m shocked that we did this well but extremely excited that we could do this for you.”

Catherine, you are a true joy and an inspiration to us all. Thank You!!
Riding For AA&MDSIF

Riding For AA&MDSIF just held its 7th Annual Middlesex Century 100-mile bike ride! Friends and families have raised nearly $18,000, but their goal is to raise the $60,000 for AA&MDSIF to provide a research grant named in Sam’s honor. Their hard work and determination has turned into a great legacy honoring the life of Samuel Jordan, an actor, playwright and producer.

Despite the record-setting temperatures in the Boston area on August 25th, 2007, many cyclists participated. The Middlesex Century is a bike ride created to raise funds for, and awareness of, aplastic anemia and myelodysplastic syndromes. In July of 2000, Samuel Jordan was diagnosed with aplastic anemia. Since then, his friends and family contribute to this annual event to try to make a difference for all those diagnosed with these diseases. See photo below.

The bike ride twists through the roads and towns of Middlesex County, just outside of Boston. Five riders completed the 100-mile route while nine other riders completed a 30-mile version of the ride. The smaller route made a loop meeting up with the century riders for the last 15 miles of both rides.

Thank you to all the riders and organizers for everything you do!

For more information about the ride, getting involved or participating, please visit www.bencode.com/ride.

Revised Warnings and Adverse Reactions for Exjade®

In May, the Food and Drug Administration (FDA) announced that the agency and the manufacturer Novartis had notified “healthcare professionals of changes to the warnings and adverse reactions sections of the product labeling for deferasirox (Exjade®), a drug used to treat chronic iron overload due to blood transfusions (transfusional hemosiderosis) in patients 2 years of age and older.” Cases of acute kidney failure had been reported after Exjade® came onto the market; some of the patients unfortunately died. The majority of the deaths, however, occurred in patients who had several other medical problems in addition to the iron overload and whose hematological disorders had progressed significantly. Besides the reports of deaths, there were “reports of cytopenias [low blood counts], including agranulocytosis [low red blood cells], neutropenia [low white blood cells] and thrombocytopenia [low platelets] in patients treated with Exjade where some of the patients died…. Further, cases of leukocytoclastic vasculitis [inflammation of blood vessels], urticaria [hives], and hypersensitivity reactions [including anaphylaxis and angioedema] were reported.” Still it is not known how these problems are related to the use of Exjade®.

Continued on page 10...

New and Returning Staff

Leigh Clark
Patient Educator
clark@aamds.org
Leigh recently joined the AA&MDSIF as a patient educator. She communicates with patients and families all over the world by telephone or email, providing answers, support, and hope. Leigh helps patients, family members, caregivers, and medical professionals by answering questions about bone marrow failure diseases and treatments, by finding financial resources, and providing them with educational materials. She brings to the foundation more than 18 years experience as a patient advocate, most recently with United Cerebral Palsy of Southern Maryland.

Julie Bast
Donor Support Coordinator
bast@aamds.org
Julie returns to the AA&MDSIF after a short leave of absence, and she brings with her a large amount of institutional knowledge. Julie assists with fundraising events and donation requests. She will guide and support you throughout your event and answer any questions you may have about making donations in honor of a loved one. Julie also organizes and maintains our research grant files and helps the financial manager as needed with our confidential patient information database and other organizational duties that help keep the office running smoothly.
Ways to Support the AA&MDSIF at Work

Combined Federal Campaign

Please encourage your co-workers to donate to the AA&MDSIF (Agency 10302) through the Combined Federal Campaign or other workplace giving program. Designating AA&MDSIF will allow us to fund medical research to seek a cure, provide patient assistance and emotional support, and distribute educational materials and updated medical information.

‘Tis the Season – Holiday Shopping Online

Do you holiday shop online? Shopping through iGive.com will raise money for the AA&MDSIF. iGive.com provides links to major online shopping outlets such as Nordstrom, Barnes and Noble, Gap, Best Buy, Target, Lands End, and many, many more. Be sure to list Aplastic Anemia & MDS International Foundation as your chosen charity and shop ‘til you drop. There is no cost to you for using the service. It’s that easy! Ask your friends and family to do the same!

GoodSearch.com

Google, Yahoo, Alta Vista... do you use these search engines to surf the web? Now you can use GoodSearch.com. GoodSearch.com is powered by Yahoo! It’s simple and each time you use GoodSearch.com, money is generated for the Foundation. Make GoodSearch.com your main search engine, choose the Aplastic Anemia & MDS International Foundation as your charity and you don’t even have to leave your chair to raise money.

Together we can work to find a cure!

Monthly Pledge

Want to help, but not sure how? How about signing up to be a monthly donor with the AA&MDSIF. Your monthly pledge will help us provide patient assistance and emotional support, distribute educational materials and updated medical information, and fund medical research to find a cure. Anyone can sign up by sending in a completed Monthly Pledge Form by going to our website, www.aamds.org, choose donate on the left and then select “ways to give” to see the list of choices or call 800.747.2820/410.867.0242. It’s that easy!!

First Giving

www.firstgiving.com personal fundraising pages can be used by anyone or any group that wishes to help raise money to support AA&MDSIF and our search for a cure. The fundraising pages can be used by supporters, for any reason at all: dinner party, marathon runner, in memory of someone, etc. Nine fundraising pages have been set up and have generated $2,775 since the November 2006 eBulletin!

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Revised Warnings (cont. from page 9)

The FDA advises “(h) ealthcare professionals... (t)o) monitor serum creatinine in patients who are at increased risk of complications, have preexisting renal (kidney) conditions, are elderly, have co-morbid conditions, or are receiving medicinal products that depress renal function. Blood counts should also be monitored regularly and treatment should be interrupted in patients who develop unexplained cytopenia.” Patients can find out more by talking with their treating physician and by reading more at http://www.fda.gov/medwatch/safety/2007/safety07.htm#Exjade.

Marrowforums Anniversary

August 1, 2007 marked the first anniversary of Marrowforums.org, a free website and discussion forum for patients with bone marrow failure diseases, their families and caregivers. Forum members discuss their illnesses, answer each other’s questions, share information, and support each other. The discussion topics include specific diseases and treatments, as well as related medical and everyday practical issues.

Marrowforums was created and is run by aplastic anemia and MDS patient Ruth Cuadra and caregivers Neil Cuadra and Vince Wessling, to take advantage of the incredible support that patients can give each other. Marrowforums has experienced steady growth since it opened, as patients from all over the world are referred to the website by the AA&MDSIF or find it on their own while searching the web for information about their disease.

If you or somebody you care about would like to communicate with others facing similar issues and circumstances, you are welcome to join the discussions at Marrowforums. It’s available as a resource for you and your family 24 hours a day, and registration is free.
### Ribbon Magnets
Our new car ribbon magnets are an excellent way of creating awareness by just driving your car! Buy some extra for your friends and family, too!

<table>
<thead>
<tr>
<th>Ribbon Magnets</th>
<th>$10 per magnet or 2 for $15</th>
<th>Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Magnets</td>
<td></td>
<td>_____</td>
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</tbody>
</table>

### Blood Drop Plaque
For a donation of $200, a brass plate will be engraved with your loved one's name and mounted on the stunning carved mahogany blood drop sculpture displayed at the office and conferences.

<table>
<thead>
<tr>
<th>Blood Drop Plaque</th>
<th>$200 per plaque</th>
<th>Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name of Person Honored:</td>
<td></td>
<td>_____</td>
</tr>
<tr>
<td>Name of Person Giving Gift:</td>
<td></td>
<td>_____</td>
</tr>
</tbody>
</table>

### Awareness Campaign Bracelets
Bring awareness of bone marrow failure disease within your community with these bracelets. Increase visibility by wearing your bracelet and getting people to ask about it. The bracelets red and white color combination is symbolic of the red and white blood cells found in bone marrow; “BRAVERY” is something those living with bone marrow failure are admired for – the bravery they demonstrate living with this disease on a daily basis. Your donation will begin working to help people become more aware of bone marrow failure disease as soon as you start wearing your bracelet or give them a bravery bracelet of their own to wear!

<table>
<thead>
<tr>
<th>Awareness Campaign Bracelets</th>
<th>$10 per package x _____# pkgs (10 bracelets are in each package)</th>
<th>Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Packages</td>
<td></td>
<td>_____</td>
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</tbody>
</table>

### Total

PLEASE PRINT CLEARLY
<table>
<thead>
<tr>
<th>Name</th>
<th>Shipping Address</th>
<th>City</th>
<th>State</th>
<th>Zip</th>
<th>Phone with area code</th>
<th>Email</th>
<th>Please Make Checks Payable to: AA&amp;MDSIF</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>☐ Check ☐ Money Order ☐ VISA ☐ MasterCard</td>
</tr>
</tbody>
</table>

Credit Card Number ________________________________
Card Expiration Date ________________________________
Signature of Card Holder ________________________________

If paying by credit card, FAX this form to 410.867.0240
If paying by check, mail check along with this form to the above address
Please allow 1-2 weeks for delivery.
For the latest information, news and updates, visit our website www.aamds.org regularly

Watch for updates about:

- New drug and treatment announcements
- Medicare and insurance coverage information
- Highlights from the 2007 Patient and Family Conference
- New and revised publications
- Announcements about the 2008 Patient and Family Conference in Washington, DC
- Special AA&MDSIF 25th Anniversary celebrations

And much, much more