Treatment Adherence: Helping You Travel the Sometimes Rough Road of Bone Marrow Failure Diseases

AA&MDSIF’s Standing Up for Your Health program encourages you to be an effective self-advocate to get the most out of your relationship with your healthcare provider and to learn about your disease and treatment options. Taking a positive step such as selecting a treatment option is a move toward living well with MDS, aplastic anemia, or PNH. Staying on your chosen treatment plan increases the likelihood of treatment being effective.

Effective treatment may mean fewer transfusions and more energy and time to embrace life. We know from studies that many patients may feel worse before they begin to feel better when using some of the medications approved to treat bone marrow failure diseases. Staying on a treatment long enough to gain maximum benefit is an important next step. Many patients need to take one of these drugs for a few months before they feel any positive effects. This is important to remember, even

Continued on page 3

AA&MDSIF Establishes Groundbreaking MDS Clinical Research Consortium

In July 2012, AA&MDSIF announced the establishment of an unprecedented, six-institution consortium designed to undertake unique studies and trials to significantly advance treatments and improve outcomes for patients with myelodysplastic syndromes (MDS). Known as the MDS Clinical Research Consortium, the five-year, $16 million initiative is sponsored by the Aplastic Anemia & MDS International Foundation (AA&MDSIF) and supported by the Edward P. Evans Foundation.

A new cooperative venture

The consortium will fill a major gap in MDS-related clinical research in the United States by providing a new “critical mass” of patients and patient data to support the evaluation of promising new compounds, epidemiological studies, and translational studies leading to new classifications, treatments, and procedures. Concurrently, AA&MDSIF will expand its programs for MDS patients, families, caregivers, and local physicians that support and complement the aims and purposes of the Consortium and thus contribute to its impact and success.

“One of the greatest challenges in research of rare diseases like MDS is having enough patients to conduct meaningful clinical trials. No single center can do it alone. This uniquely collaborative effort overcomes that barrier,” said John Huber, AA&MDSIF’s Executive Director. “To have these six leading MDS research centers working together in this way is unprecedented.”

Continued on page 3
Long before he became the “king of late night television,” Johnny Carson hosted a program called “Who Do You Trust?” The premise of the show was whether the husband or wife would be best able to answer a question and win some money.

Today, in a world of millions of pages of information readily accessible to anyone with a computer or a smartphone, the question is even more important—who can you trust?

It’s one thing to check Consumer Reports or Angie’s List or the Better Business Bureau when looking for a new car, a plumber, or realtor. It’s an entirely different matter when you are looking for the most accurate and current information about a life-threatening disease. Access to information is not the issue; discerning what is of value is. That is why every one of our publications and all of the information on our website is reviewed and approved by the world’s leading experts in bone marrow failure diseases. All new information is vetted by members of our Medical Advisory Board and Patient Education Council before it is posted to our website or included in any of our publications.

This ensures that information you may be using to make critical medical decisions with your doctor is accurate, complete, and unbiased. We take great care so that you can be confident in our patient education materials – that you can trust us.

Similarly, we trust you. No one knows what services you need and want better than you do. That is why we listen very carefully to what you tell us. Your feedback—both kudos and complaints—are welcome and heard. While we know we can’t do everything that everyone might want, we can always try to do what we do better.

Finally, there is another kind of trust that we value very highly—the trust our donors place in us to use their contributions wisely and effectively. We place a premium on maintaining and guarding that trust.

Our stewardship of every one of the dollars entrusted to us has been recognized by Charity Navigator—the largest “watchdog” group for nonprofit organizations—with their highest rating for EIGHT consecutive years. This recognition for our fiscal integrity, programmatic excellence and governance responsibility places us in the TOP 1% of all charities and nonprofits in the United States. No other bone marrow failure disease organization can make that statement.

So, the next time you are asked, “Who do you trust?”, you can answer—AA&MDSIF. You can trust us for answers, support, and hope.

Stay well,

John M. Huber
Executive Director
when the road you and your doctor decide to take gets bumpy and hard to travel. AA&MDSIF asked patients, doctors, and nurses about the challenges to staying on the treatment journey. What we learned in our survey can help you be your own best advocate—making the most of every office visit.

Anyone who has ever made a long road trip knows that there are many things you can do in advance to prepare for a difficult journey. You and your doctor will map out the course you will take by first determining your treatment goals (think of this as your ultimate destination). Once that is decided, you can both do a number of things to help make the trip as smooth as possible.

One of the things we learned in our survey was that communication between physicians and patients may not be as good as it needs to be. This is the equivalent of not giving and not listening to directions before you venture out on your journey.

Physicians can do a better job of educating bone marrow failure disease patients about their disease, available treatment options, and the potential side effects they might experience. Gathering information about your disease and its impact is like reading your vehicle owner’s manual.

Your physician and healthcare team can identify where you might have trouble with your engine and can make recommendations on how to keep you on the road. Physicians can help patients choose the best treatment option for them. They can help by explaining the potential side effects (e.g. feeling sick, fatigue) of the available treatments, much like the hazard warnings along a highway.

A patient can take steps to avoid or adapt their driving to get past those potholes, falling rocks, and hairpin turns on the treatment highway.

Continued on page 12
Welcome to our 2011 Annual Report and Honor Roll of Donors
Giving Patients and Families a Lifeline of Answers, Support, and Hope

Each year, AA&MDSIF summarizes our activity to show you how our mission—bringing answers, support, and hope to patients and families affected by bone marrow failure diseases—is achieved. You’ll read about what we’ve been doing, how we meet the needs of our constituency, and you’ll also meet our patients and families, generous supporters, and donors.

As we approach our 30th Anniversary, AA&MDSIF is helping more patients and families than ever before with more programs and services that are effectively providing them with answers, support, and hope. All this is made possible thanks to the generosity of patients, families, foundations, and corporations who express their commitment to fighting bone marrow failure diseases through their giving to AA&MDSIF.

From my personal experience as the spouse of a patient fighting a bone marrow failure disease, I know how important AA&MDSIF is to patients and families throughout their journey with aplastic anemia, MDS, and/or PNH. This organization is committed to ensuring that everyone diagnosed with one of these diseases can benefit from its educational programs, research updates, and patient services.

The strategic priorities adopted by AA&MDSIF’s Board of Directors in July 2010 are reflected in our accomplishments in 2011, the programs underway in 2012, and the plans being made for 2013 when we celebrate three decades of service. Most significant is the announcement of the MDS Clinical Research Consortium. This unprecedented, six-institution consortium is designed to undertake unique studies and trials to significantly advance treatments and improve outcomes for patients with myelodysplastic syndromes (MDS). This five-year, $16 million initiative is sponsored by AA&MDSIF and supported by the Edward P. Evans Foundation.

AA&MDSIF is also moving forward in its programs for aplastic anemia and PNH patients. Projects include adding content to the Online Learning Center and continuing to build Communities of Hope.

To expand programs and to provide support to an increasing number of people, the generosity of our patients, families and friends is vital. We encourage you to give the best gift you can to ensure that our work continues for you…and for every person who will be diagnosed with one of these diseases in the years ahead. As part of our public commitment as a 501(c)3 charitable organization, we are pleased to provide a financial overview for you. Please visit www.AAMDS.org to see a copy of our recent audits and IRS Form 990s, and learn more about ways you can help patients and families through AA&MDSIF.

In FY2011, our most recently audited year, AA&MDSIF received $2.67m in charitable contributions and philanthropic support toward $2.67m in expenses. 83% of the budget went toward programs and services. For FY2012, AA&MDSIF’s budget for revenue is $3.5m to meet the need for more programs on a wider array of topics, more immediate access to research findings, and more awareness about these diseases. We are proud that for the 8th consecutive year, we have received the top rating of 4 stars from Charity Navigator, America’s largest independent evaluator of charities.

On behalf of our Board of Directors, thank you for your continued commitment to the 30,000+ patients and families we are helping now…and the thousands who will call on us in the coming year. For them – and perhaps for you, as it has been for me and my family -- AA&MDSIF is an important lifeline. Thank you.

Kevin Lyons-Tarr
Chair, AA&MDSIF Board of Directors
AA&MDSIF 2011 Highlights

Patient Education

Educating patients, in person, online, in print

Our goal is to be the resource of choice for learning about aplastic anemia, MDS, and PNH.

We offer an array of print and online educational materials in easy-to-understand lay language, as well as live learning events featuring experts in bone marrow failure diseases and “living well” topics.

When patients reach out – AA&MDSIF is there with immediate help.

“Your materials make a huge difference because they help me be my own strong advocate.” – Joan, MDS patient

Our patient information packet contains easy-to-understand single-topic fact sheets, in-depth patient guides, and information about our in-person and online learning opportunities. Nearly 900 packets were mailed in 2011, all within 48 hours of the request being received.

New regional patient and family conference series supports more attendees.

“Thanks to AA&MDSIF for doing conferences like this all over the country. Not all of us can get to a single national conference every year.” – Adam, aplastic anemia patient

Based on input from our annual conference attendees, our new regional patient and family conference series got off to a great start in 2011 with six one-day conferences around the country. This enabled us to serve well over three times as many patients and families than was possible with our earlier national conference.

The Online Learning Center expands content and reaches patients where they are.

“The live webinars, webcasts, and interviews are an invaluable source of information about bone marrow failure diseases such as mine. Thank you very much for the knowledge and support you provide.” – Patricia, MDS patient

In 2011, the Online Learning Center (www.AAMDS.org/Learn) added to each of its four content formats, including 20 all-new webinars attracting over 1,000 viewers. Between live webinars, prerecorded webcasts and interviews with experts, and interactive learning modules that bring viewers up to speed on important topics, this is a remarkable learning opportunity in one location.

The MDS Connection presents information from experts and inspiring stories from patients.

“The MDS Connection is great! I look forward to their arrival. I like to know what is going on in the research area and new treatments and keep current. I also like reading about other patients’ feelings and perspectives.” – Norma, MDS patient

The MDS Connection is a six page print publication published six times a year, bringing interviews from acknowledged experts and personal stories and perspective from MDS patients straight to 13,000 mailboxes. Cover topics have included: Treatment Issues; Getting Expert Care; Advances in Research; Managing Fatigue, and more.

The latest scientific research is succinctly summarized for patients and families.

Every year, AA&MDSIF produces three booklets summarizing key research findings presented at the American Society of Hematology (ASH) meeting. These plain-language booklets contain the information experts believe are most important and helpful to patients. 2011 ASH summary booklets on aplastic anemia, MDS, and PNH are available online at www.AAMDS.org/ASH2011update. If you prefer, you can request print copies of the MDS and PNH booklets (aplastic anemia summary is available as download only) to be mailed to you by contacting harper@aamds.org or by calling (301) 279-7202 x116.
Patient Support
Supporting patients and families through multiple means
AA&MDSIF’s one-to-one patient support provides knowledge and compassion.

2011 brings a significant increase in first-time inquiries.
In 2011, AA&MDSIF’s Patient Educator responded to nearly 4,000 phone and email inquiries, almost twice the amount received in the prior year.

Question can include:
• How should I tell my family I am ill?
• How do I find an expert?
• How can I find a bone marrow donor?
• What are the side effects of treatments vs. the actual disease?

Patients and families are asking questions, obtaining information on clinical treatment centers, requesting a peer support network volunteer, expressing concerns about their insurance coverage, or seeking clarification after an appointment with their doctor.

The Community of Hope program makes a bright start as a support group program that patients and families can make their own.

“I have participated in bi-monthly meetings that have covered a wide variety of topics, ranging from the medical (understanding your lab reports to treatment options) to the social (the importance of humor and laughter). I am so fortunate to have found our group, and I look forward to our meetings.”
– Elizabeth, MDS patient

These AA&MDSIF-affiliated, volunteer-led local support groups are ongoing, local organizations created by patients and families to create support in the community setting.

In 2011, eight Community of Hope groups were started in the following cities: Seattle; Phoenix; Asheville and Raleigh areas of North Carolina; Cincinnati; Central New Jersey; Lima, Ohio; and Middletown, Connecticut.

Have you been meaning to give to AA&MDSIF this year?

“I have been meaning to make my gift to AA&MDSIF. You helped save my husband’s life. Thank you.”

PLEASE JOIN OTHER PATIENTS AND FAMILIES BY MAKING YOUR GIFT TODAY.

Give securely online at www.aamds.org/donatenow or by mail using the enclosed gift envelope.

You can’t do it alone…and neither can we! Thank you.

Marrow forums
“We discovered a wonderful community at the Marrowforums Web site. Instead of seeing statistics, we shared the day-to-day struggles and triumphs of others with similar diagnoses and learned much about these rare diseases.”
– Karen, MDS patient

The Peer Support Network creates connections for sharing patient-to-patient advice, support, and compassion.

“As a Peer Support Network volunteer for the past seven years, I have had the opportunity to speak with mothers whose children were going through the difficult process of learning about and dealing with aplastic anemia. Talking with these other parents reminds me that it is important to share our stories, and this can provide a good way of coping.”
– Paige, mother of aplastic anemia patient

The Peer Support Network (PSN) is a national network of over 50 trained volunteers, including patients, caregivers, and family members who offer information, personal experience, coping strategies, problem solving skills, and informational resources to people just like themselves. Patients are connected with each other through our Patient Support department.

Patients are connecting online at www.Marrowforums.org
Professional Education

Engaging With Healthcare Professionals

As partners in patient care, AA&MDSIF provides health professionals with targeted educational programs and materials, and support at major conferences.

The Treating MDS toolkit helps medical professionals educate their patients about MDS.

AA&MDSIF launched the Treating MDS toolkit, a free resource developed to provide community hematologists and oncologists with materials to help communicate with and support their MDS patients.

The toolkit contains a counseling guide and an array of patient information sheets that can be distributed to patients at the physician’s or nurse’s discretion. With more than 200 toolkits distributed, AA&MDSIF’s outreach to physicians encountering MDS is making an impact on patient care.

Our mobile app for MDS Risk Classification and Stratification goes live, with worldwide usage.

A free mobile app for smartphones was developed to assist physicians with risk stratification and selection of treatment options for MDS patients and is available for Android, BlackBerry, and iPhone platforms, with an iPad version in development.

With context-sensitive informational screens for users, it includes medical calculators for IPSS, WPSS, FAB, and WHO classification systems. To date, the app has been download more than 1,500 times from over 50 different countries.

AA&MDSIF attends the American Society of Hematology Annual Meeting

Nearly 300 hematologists participated in an AA&MDSIF-sponsored educational session, “Successes in Bone Marrow Failures” satellite symposium, co-sponsored with the Cleveland Clinic. The symposium was held at the American Society of Hematology (ASH) annual meeting in San Diego, CA in December 2011.

Hematologists and related health professionals also learned more about AA&MDSIF when they met with Foundation staff at our exhibit booth.

AA&MDSIF also sponsored an exhibit at the American Society of Clinical Oncology (ASCO) 2011 Annual Meeting in Chicago and the Oncology Nursing Society Annual Congress in Boston.

Inaugural MDS/MPN Rounds Program in Chicago a Success

AA&MDSIF joined with the MPN Research Foundation to present the first MDS/MPN Rounds program for health professionals in Chicago in September, 2011.

Dr. Laura Michaelis of Loyola University speaks at the MDS/MPN Rounds event in Chicago.

The MDS/MPN Rounds Program is a forum for health care professionals in the Chicago area to address issues related to the diagnosis and treatment of patients with myelodysplastic syndromes or myeloproliferative neoplasms.

Sixty-five clinicians participated in the program, which featured lively discussion of cases in both disease areas and comments by guest speaker Jerry Radich, MD, of the University of Washington School of Medicine. Participants were able to network, share best practices, and learn the latest information on new therapies and advances in the management of MDS and MPN through interactive case studies presented by experts in greater Chicago.
Funding research fuels scientific advances.
AA&MDSIF has provided over three million dollars in grants to over 50 domestic and international researchers studying bone marrow failure diseases. Two-year $60,000 grants are awarded annually.

NEW GRANTS: 2011-2013

AA&MDSIF Torry Yahn Research Grant
Kim-Hien T. Dao, DO, PhD, Oregon Health & Science University for Beta-catenin is a Molecular Target of the Fanconi Anemia Core Complex

AA&MDSIF PNH Research and Support Foundation Grant
Keith R. McCrae, MD, Cleveland Clinic for Circulating Microparticles in PNH

AA&MDSIF Trinity Ewert Research Grant
Parinda Mehta, MD, Cincinnati Children’s Hospital Medical Center for Quercetin in Patients with Fanconi Anemia, a Pilot Study

GRANTS IN PROGRESS: 2010-2012

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.

Gregory A. Abel, MD, Dana-Farber Cancer Institute for Developing a Disease-Specific Measure for Quality of Life in Patients with Myelodysplastic Syndromes (MDS)

AA&MDSIF Emily Kass Research Grant
Cristian Bellodi, PhD, University of California, San Francisco for p53 Translation Control in Hematopoietic Stem Cell Quiescence and Differentiation

Help AA&MDSIF Find Better Treatments and a Cure!

Join families like the Yahns in funding research through AA&MDSIF!

• Give to a “Research is Hope” Fund (minimum gift $5,000) to combine your support with similar gifts from other patients and families toward a research grant.

• Establish a Named Research Fund ($60,000 minimum; can be donated/raised over 3 years).

Direct your gift to aplastic anemia, MDS, PNH, or general bone marrow failure disease research. You’ll receive annual updates on research funded through your support. To talk about your interests, contact Sandra Walter-Steinberg at (301) 279-7202 x104 or walter@aamds.org. Thank you!
Advocacy and Public Affairs

Advocacy 2011: Keeping important legislation in view, and moving forward

Despite a challenging fiscal and political climate, Representative Doris Matsui (D-CA) reiterated her commitment to federally-supported legislation and programs designed to bring us closer to new cures for bone marrow failure diseases.

H.R. 640: On February 10, 2011, Rep. Matsui reintroduced the Bone Marrow Failure Disease Research and Treatment Act, which would authorize $8 million over five years for surveillance, outreach, and improved diagnostic practices for aplastic anemia, MDS, PNH, and other bone marrow failure diseases.

We’re growing our use of social media.

Our social media presence continued to expand in 2011, providing patients and families with more ways to connect with us and each other.

With over 3,000 followers, the AA&MDSIF Facebook page (www.facebook.com/aamds) has rapidly grown.

Our YouTube channel, (www.YouTube.com/aamdsif) features expert interviews, patients telling their stories and sharing their experiences, and coverage of community and awareness events.

AA&MDSIF volunteer events raise funds and build community spirit.

AA&MDSIF patients, families, and friends held numerous successful events in 2011, through a variety of community fundraising and awareness projects. Here’s what our volunteer network accomplished:

- 32+ fundraising/awareness events were held, 20 of which were new
- 300+ volunteers helping at all events
- Nearly $250,000 was raised from all events!

www.AAMDS.org is relaunched in 2011.

Redesigned to be an even better resource to serve the bone marrow failure disease community, the redesigned AA&MDSIF Web site was officially launched on July 15, 2011. With a fresh new appearance, expanded content, and streamlined navigation, visitors can locate the information they seek through several avenues of access -- by disease type, by audience type, or by specific AA&MDSIF program.

Top 10 pages visited on our new Web site.

- Home page
- FAQ
- Aplastic Anemia
- MDS
- Patients and Caregivers
- Stories of Hope
- About Us
- Conferences
- Glossary
- Aplastic Anemia Treatment

www.AAMDS.org | Fall 2012
Our thanks to those individuals, corporations, foundations, and organizations which made contributions to fund AA&MDSIF’s programs and services during 2011. We honor all of our generous supporters, with additional thanks here to those who have given $500 or more during the 2011.

Every effort has been made to accurately acknowledge all contributors who gave $500 or more cumulatively between January 1, 2011 and December 31, 2011. If you would like to report an error or omission, please call Sandra Walter-Steinberg at (301) 279-7202 x104 or email walter@aamds.org. We apologize for any inadvertent errors and thank each of you for your generosity.

Chairman’s Circle ($100,000+)
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* Matching Gifts
2011 Corporate Leadership Circle

AA&MDSIF thanks our corporate supporters for their generosity and commitment during 2011 to fighting bone marrow failure diseases through the work of AA&MDSIF.

With almost 30 years as an effective volunteer health organization, AA&MDSIF presents a growing list of exciting national partnership opportunities for companies and organizations that care about helping patients and families facing aplastic anemia, MDS, PNH, and other bone marrow failure diseases. For more information, contact Industry Relations Manager Ramona Crawford at (301) 279-7202 x117 or crawford@aamds.org.

Platinum Level

Celgene Corporation

Gold Level

Alexion Pharmaceuticals

Silver Level

Otsuka America Pharmaceuticals

Bronze

Novartis

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Cleveland Clinic Foundation

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Imedex Rockpointe

MPN Research University of Maryland Foundation Medical Center

Named Program and Research Funds 2011

Major support has been provided by family and friends to support programs and medical research through AA&MDSIF in their loved ones’ names. We thank them for their extraordinary commitment to advance the understanding and search for a cure for aplastic anemia, MDS, PNH, and other bone marrow failure diseases.

Research is Hope

Marissa Marie Amuso

Jack Byrne

Holly Cataldo

Matthew DeBono Scholarship Fund

Trinity Ewert

Michael Fernandes

Steve and Joanna Janowiak

Sam Jordan

Emily Kass

Caitlyn Langley

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PNH Foundation

Providing New Hope

Pursuing New Hope

Mary Lou Palacio

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Harold Spielberg

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Torry Yahn

* Named Research Funds

Special Fundraising Events in 2011

Visionaries $30,000+

*AA&MDSIF Matthew DeBono Memorial Scholarship Fund Picnic – Sally and Manuel DeBono and family – Indianapolis, IN

Jackson County Brevet in honor of Kelly Wilhite - Robert Wilhite, Atlanta, GA

*Hope, Steps & A Cure Walk / Los Angeles - Stephanie Hamm, Ruth Cuadra, Susan Kass, Jennifer Barrios, Gig Hollaback, Tammy Martinez, Candy Stoutenborough, Kelley Tremelling, Mary Elaine Valenzuela, Nina Van Nostrand, and Sheila Wilkerson

Torry Yahn BBQ and Auction to benefit the AA&MDSIF Torry Yahn Research Fund - JoAnn and Don Yahn, Churchville, NY

Patrons $10,000-$29,999

*Hope, Steps & A Cure Walk / San Antonio - Monica Fairchild, Stephanie Hamm, Carmen Romo de Vivar, Ginger Caron, Haley Caron, and Patty Sprain

*Taubman Asset Group Hope, Steps & A Cure Walk- in memory of Leah Davidson, Bloomfield Hills, MI

Benefactors $5,000-$9,999

Judy Joyce Memorial Golf Tournament - Robert and Brenda Plasse, Woonsocket, RI

Michael’s Fight 5K Run/Walk in memory of Michael Lobberg-Luz Campo, Coral Springs, FL

Firstgiving.com Campaign to benefit the AA&MDSIF Amber Lynn Wakefield Research Fund - Jessica Winchenbach, San Diego, CA

Wing Fling to benefit the AA&MDSIF Michael Fernandes Research Fund - Kim Fernandes-Huff, North Falmouth, MA

Friends $1,000-$4,999

*Halloween Bash- Mario Rivera and Alison Hines, Edison, NJ

*Falmouth for Samantha in honor of his daughter, Samantha-Peter O’Neil, Falmouth, MA

Catherine’s Craft Fair in honor of Catherine MacLean - Connor Schmidt, Ian MacLean, and Benjamin Johnson, South Hamilton, MA

Our Hike/ Hope, Steps & A Cure Walk- Robin Grapa and Patty Laatsch, Phillips, WI

*Biking for Bravery in honor of Delia Gonzalez - Aaron and Aleena Roeschley, Rio Rico, AZ

*Classical Guitar Benefit in memory of Buddy Palaganas - Kevin Palaganas, Goldsboro, NC

Benefit Breakfast in honor of Michael Barner - Bernadette Miller, Brad Miller, and David Macon, Landisville, NJ

T.S. Gates 5K Run /2 Mile Walk in memory of Thomas Gates - Sally and Elizabeth Gates, Poquoson, VA

Jungle Jam in honor of Annalyse Kitzberger - Jeffrey and Sherri Kitzberger, Cleveland, OH

*Miles for Mom in memory of Patricia White - Steven White, Glen Allen, VA

*House Party – in memory of Mary Pat Grieshaber - Margie Ward, Hampshire, IL

*Dodgeball Competition in honor of Haley Bergin - Seton Hall Preparatory School Student Council, Michael Zinsmeister, Michael Bergin, West Orange, NJ

*Pedal for Hope – Catherine Carbonaro, Sonoma County, CA

*Mike’s Day Volleyball Tournament in memory of Michael Farreny - Scott Sweeter, Matthew Parisi, and Brian Nop, Cherry Hill, NJ

*Firstgiving.com campaign in memory of Aiden Sullivan - Jessica Rounce, Kingsland, GA

*Team Leggs Ironman Triathlon Event in honor of Linn Campbell - Scott Sweeten, Matthew Parisi, and Brian Nop, Cherry Hill, NJ

*Tobacco Road Marathon - Steven McGill, Cary, NC

*Wicked Half Marathon in memory of Phyllis Garbis - Jason Garbis, Salem, MA

*Pedal for Hope – Catherine Carbonaro, Sonoma County, CA

*Firstgiving.com campaign in memory of Aiden Sullivan - Jessica Rounce, Kingsland, GA

*Team Leggs Ironman Triathlon Event in honor of Linn Campbell - Kelly Campbell, Louisville, KY

*Includes gifts received through online fundraising pages created by event volunteers

www.AAMDS.org | Fall 2012 11
Help Spread Awareness with our practical and stylish Marketplace items!

AA&MDSIF items are now available through our online Marketplace including our popular Bravery bracelets. 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

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.

Bravery bracelets ($10 for 10 bracelets/1 pack)
Red and white silicone bracelets, symbolic of red and white blood cells.

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

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

Clinical Research Consortium (continued from page 3)

A clinical research fellow. Known as “Edward P. Evans Fellows,” each fellow will have the opportunity to work, learn, and grow in a truly collaborative environment, and will likely become the MDS clinical research leaders of the future.

The consortium will conduct Phase I and Phase II clinical trials along with pilot studies to identify and confirm new treatments and therapies for MDS. Working collaboratively to develop and implement a clinical research agenda, the six institutions will then be able to pursue that agenda more rapidly and effectively than has ever been done previously in MDS clinical research.

“We are extremely pleased to work in partnership with AA&MDSIF and these six outstanding consortium members. This collaborative endeavor reflects Mr. Evans’ desire to support the highest quality MDS research which will lead to improved treatment for patients and ultimately to find a cure,” said an Evans Foundation trustee.

AA&MDSIF is extremely grateful to the Edward P. Evans Foundation for their vision and support in making the MDS Clinical Research Consortium a reality. Their support along with the commitment, dedication, and expertise represented by the six consortium institutions and AA&MDSIF will create a new direction for MDS clinical research, leading to better treatments for MDS patients. This effort is nothing less than revolutionary.

Treatment Adherence (continued from page 3)

Patients can do a better job of communicating their desired treatment goals and how potential side effects affect their quality of life. Let your doctor know if you are running out of gas, your engine isn’t running right, if you need to spend a little time at a rest stop, or even want to change your destination.

While it is easy to ask “are we there yet?” remember that effective treatment can take a few months before you start to feel better. But ask your physician about the signs you might notice along the way (and when to expect them) that indicate you are going in the right direction.

Do your part to become an empowered patient—you are the driver on this journey. Your body is the vehicle (late model or not—it’s what you’ve got).

Your treatment is the road and comes with the pot holes, hills, jersey barriers, and other hazards known as side effects. Your loved ones are your companions on this journey. Your physician is your personal GPS or navigator—helping to guide you along the way. Good communication to and from your doctor is key to safe travels.
Should I get a flu shot?

Summer is over, and it’s time to start thinking about fall allergies and the upcoming flu season. Should I or shouldn’t I get a flu shot is a great question and you are not alone with trying to come up with the right answer. A good resource for general flu information is the U.S. government Web site www.flu.gov. But consider these points when making your decision!

1. Consult with your hematologist before you get a flu shot. He or she can look at your unique situation and help weigh the risks and benefits of getting a flu shot. Your doctor will consider:
   - Your specific disease
   - Your medical and treatment history (including a bone marrow transplant)
   - Your current symptoms and medical status
   - Similar experiences he has had with other bone marrow failure patients and the flu vaccine

2. Talk to your doctor about whether your family members and others in close contact with you should get a flu shot. This may reduce your chance of getting the flu.

Other things to consider when talking to your doctor and making a decision:

- Getting a flu shot may help keep you from getting the flu. Speak with your doctor about the flu vaccine.

- Researchers are unclear about how well the flu vaccine works if you have a compromised immune system or if you are taking an immunosuppressive drug. The Centers for Disease Control & Prevention (CDC) notes that the following information pertains to the inactivated flu vaccine or the ‘flu shot’ only. The live attenuated influenza vaccine (LAIV) should not be considered for bone marrow failure patients.

- The flu shot can cause a low grade fever in some people. If you have a low white cell count (neutropenia), you should discuss any fever following a flu shot with your doctor.

- For bone marrow transplant patients, the Centers for Disease Control and Prevention (CDC) published Guidelines for Preventing Opportunistic Infections Among Hematopoietic Stem Cell Transplant Recipients. This document includes information about flu shots for people who have had a transplant. These guidelines generally recommend life-long seasonal flu vaccination for all transplant candidates and recipients, beginning during the flu season before the transplant and then six+ months after the transplant.

- Aplastic anemia patients should be aware that there are several medical journal articles that describe rare problems patients have experienced after a flu shot (for example, “Relapse of severe aplastic anemia after influenza immunization” published in the British Journal of Haematology in 2002). Yet those findings may not apply to you; your symptoms and disease may be very different from those patients.

Moreover, it is difficult to say that there is a direct cause and effect from the flu shot, and there are certainly many more cases where the flu vaccine has been given without incident to patients with bone marrow failure. You should also keep in mind, when talking to your doctor about your situation, that viral infections, including influenza, can suppress the blood counts, so not getting the flu shot and getting the flu may cause problems.

Some special situations:

- For PNH patients, there are also a few case reports of flares of hemolysis (when red blood cells are destroyed) after receiving a flu shot. Although case reports are not the same as randomized clinical trials, one case of hemolysis was severe enough to put the patient in the hospital.

Thus some experts recommend that PNH patients not get a flu shot, but again your case may be different. However, PNH patients who are receiving eculizumab (Soliris®) may be less likely to have hemolysis after receiving a flu shot.

- For MDS patients, experts generally recommend flu shots with the caution that the shot can cause a low-grade fever, so patients who have low white blood cell counts (neutropenia) should discuss any fevers following the vaccine with their physicians.
Volunteer Vibe

The Riveras Find Multiple Ways to Get Involved and Give Back

Fundraising events have come in all shapes, sizes, and forms with a variety of themes.

What’s the key to planning a successful fundraising and awareness event? Do what you know! And that’s exactly what Mario and Alison Rivera have successfully done in 2012. We greatly appreciate all their fundraising work over the past few years. In 2012 alone, they organized three different events!

In March 2012, Alison hosted a workplace event, “Denim Day,” as part of our Aplastic Anemia and MDS Awareness Week. For her event, her co-workers donated money for the privilege of wearing denim jeans to the workplace on a particular Friday.

In April 2012, Alison hosted an AA&MDSIF House Party. She invited family, friends, and neighbors to her house and had a jewelry party in which Lia Sophia jewelry was sold. She raised money in several ways. First, she held two raffles for a $100 Lia Sophia Shopping Spree, and 100% of the raffle proceeds went to AA&MDSIF. Second, a percentage of purchases was donated back to AA&MDSIF.

On October 20, Mario and Alison are holding the 2nd Annual Halloween Benefit Bash for Aplastic Anemia. They decided to turn their annual party into a fundraising and awareness event. There will be a minimum donation of $25 per person to attend (kids are free). Attendees will come fully decked out in their Halloween costumes for a costume contest. Other fun activities at this event include food, drinks, music, raffles, giveaways, and Halloween arts and crafts.

Take a look at our Web site (www.AAMDS.org) for some ideas or contact Martha Crews, Community Development Manager, at crews@aamds.org or (301) 279-7202 x103.

Stories of Hope

Maggie O’Neil - turning grief into actions  By Maggie O’Neil

My mom was my mentor, my idol, my confidante, and my best friend. On March 13th this year, she passed away after a short battle with MDS (myelodysplastic syndromes). I felt like I needed to do something because no one should have to go through what our family went through. I found the Aplastic Anemia & MDS International Foundation and channeled all my emotions into raising awareness and funds for these diseases.

I found a walk that happened to be in our city, Long Beach, CA, and I immediately began fundraising. After only a month, Team Pat Reep raised nearly $17,000 overall for AA&MDSIF, and on the day of the walk, April 28th, we had more than 50 people show up. I can’t even begin to thank all our family, friends, and the community for all the love and support they have shown my family and me during this dark and difficult time. We are so blessed to have such wonderful people in our lives.

Now I am fighting for the same cause by running my first marathon! I am 26 years old, and I’ve always wanted to run 26 miles at 26 years of age. I am running the LA Marathon (26.2 miles and my first full marathon) on March 17, 2013 and I am running it in memory of Mom. She always told me, “If you can imagine it, you can achieve it.” This is for you Mom, and for everyone affected by MDS.

Web exclusive

Mike Morrison’s diagnosis and treatment – planning, and persistence pay off.

About 15 months ago, I was returning home from a client visit. Because I travel regularly for work, I have the routine down to a science - grab my luggage from the overhead, make my way out of the plane and head for the shuttle to take me to the parking lot. But this time it was very different. I walked up the terminal from the plane and had to stop and catch my breath. I’ve made that walk countless times and never have I had to stop and rest. I called Mary (my better half) to let her know I had landed and told her that I was really going to have to start working out more. At the time I thought I was just getting out of shape. I had no idea what journey I was about to embark upon.

Read all of Mike Morrison’s Story of Hope online at www.AAMDS.org/Hope
Free Phone Support for Personal Attention

Do you need to speak with someone directly? Please contact Leigh Clark, our Patient Educator, at (800) 747-2820, option 1, or by email at info@aamds.org. Leigh communicates with people all over the world, answering a wide range of questions, including information on treatment options, clinical trials, financial resources, and more.

PEER SUPPORT NETWORK
Let this AA&MDSIF resource help you!

The Peer Support Network is a national network of trained volunteers, including patients, caregivers, and family members, who offer information, personal experience, coping strategies, problem solving skills, and informational resources to people just like themselves. Speaking with a Peer Support Network volunteer is a great way to gather information and receive emotional support from someone whose life has also been affected by bone marrow failure disease.

Call now!
To connect with a Peer Support Network volunteer, call (800) 747-2820, option 1, and speak with our patient educator, Leigh Clark, who will match you with one of our volunteers. You can also email her at info@aamds.org.

AA&MDSIF Webinars and Webcasts

AA&MDSIF presents webinars by some of the nation’s top experts in bone marrow failure diseases and on living well with these diseases. For more information or to register for upcoming webinars, visit our Online Learning Center at www.AAMDS.org/Learn.

Join the AA&MDSIF Facebook Community at www.facebook.com/aamds

Over 3,000 people communicate with each other and with AA&MDSIF through our active and informative Facebook page.

Follow Us on Twitter at www.twitter.com/aamdsif

Meet Up On

Marrowforums

Marrowforums hosts free online discussions about bone marrow failure disease. Ask questions. Exchange information and support. Marrowforums is run by patients and caregivers just like you! Register now at www.Marrowforums.org.

Free Patient Guides, Fact Sheets, and Additional Resources

Request a patient packet from AA&MDSIF, containing a patient guide on aplastic anemia, MDS, or PNH, and fact sheets with critical information for all bone marrow failure disease patients, families, and caregivers.

Brochures and Fact Sheets

- AA&MDSIF Advocacy
- AA&MDSIF Brochure
- AA&MDSIF Social Media
- Bone Marrow and Stem Cell Transplantation*
- Clinical Trials*
- Communities of Hope
- Financial Resources
- How to Evaluate Health Information on the Internet
- Iron Overload
- Marrowforums Hosted Online Discussions
- Online Learning Center

Patient Guides

- Your Guide to Understanding Aplastic Anemia**
- Your Guide to Understanding MDS**
- Your Guide to Understanding PNH
- Living Well With Bone Marrow Failure Disease*
- Standing Up for Your Health
- What to Expect From Treatment: A Guide to Understanding FDA-Approved Drug Therapies for Myelodysplastic Syndromes (MDS)

* Available in Spanish
** Available in Spanish and French

To order a patient packet, call (301) 279-7202 x116, or order online at www.AAMDS.org/Info.
Checklist for Fall 2012

Learn More Inside and Online

- Read about the newly-created AA&MDSIF Clinical Research Consortium, www.AAMDS.org/Consortium. [pg.1]
- Learn about the importance of adhering to your treatment program to make the progress you want. [pg.1]
- Read the AA&MDSIF 2011 Annual Report. [pg.4]
- Read Facts for Life: Should You Get a Flu Shot? [pg.13]
- See how dedicated and creative AAM&DSIF volunteers are making a difference! [pg.14]

Take Action

- Dedicate a day in honor or memory of a loved one or to celebrate your own life, on our 2012 Calendar of Hope. www.AAMDS.org/Dedication.
- Put AA&MDSIF in your will and become a Guardian of Hope. Contact walter@aamds.org or call (301) 279-7202 x104.
- Help create a Community of Hope in your area. Contact crews@aamds.org or call (301) 279-7202 x103.

What are Bone Marrow Failure Diseases?

Aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH) are rare bone marrow failure diseases.

Aplastic Anemia

Aplastic anemia occurs when the bone marrow stops making enough red blood cells, white blood cells, or platelets for the body. Any blood cells the bone marrow makes are normal, but there are not enough of them. Aplastic anemia can be moderate, severe, or very severe.

Myelodysplastic Syndromes (MDS)

MDS is a group of disorders where the bone marrow does not make enough healthy blood cells. All MDS types have a low blood cell count for at least one blood cell type (red blood cells, white blood cells, or platelets), and the bone marrow and blood contain some blood cells that are abnormal in shape, size, or function.

Paroxysmal Nocturnal Hemoglobinuria (PNH)

PNH is a blood disease that causes red blood cells to break apart, a process called hemolysis. The broken cells are then released in your urine.

Approximately 15,000 to 18,000 people in the United States are diagnosed with one of these diseases every year. AA&MDSIF provides answers, support and hope for patients, families, and caregivers whose lives are impacted by bone marrow failure diseases.

For complete descriptions, please visit www.AAMDS.org/Diseases