“When it seemed there were no answers, and little hope, AA&MDSIF provided plenty of both. 'Answers, Support and Hope' are what the Foundation is all about.”

Gloria, aplastic anemia and PNH survivor
Dear Friends,

Annual reports are loaded with facts, figures, names, numbers, and dollars. Nothing wrong with that, as all of those things are very important. But sometimes these reports are missing something vital -- people.

And organizations like ours are all about people.

Our 2014 Annual Report includes all the facts and figures, but what it also gives you is a good look at our programs and services through the eyes and words of the people we’ve served, helped, or supported as well as the people who have helped us.

These "people stories" give just a small glimpse of what we do, who we serve, and what you have made possible through your confidence in us and as partners in our work.

Thank you for all you’ve helped us accomplish in 2014. With your continued support, we will be able to do even more -- for people.

Stay well,

Kevin Lyons-Tarr
Chairman, Board of Directors

John M. Huber
Executive Director
Mission

The Aplastic Anemia & MDS International Foundation (AA&MDSIF) is the world’s leading nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, myelodysplastic syndromes (MDS), paroxysmal nocturnal hemoglobinuria (PNH), and related bone marrow failure diseases. AA&MDSIF provides answers, support, and hope to thousands of patients and their families around the world.

Vision

We are a patient-focused, patient-centered organization, serving patients and families throughout the three phases of bone marrow failure diseases:

- The life-changing phase of diagnosis
- The life-threatening phase of treatment
- The life-long phase of living with a chronic disease

Values

- Accountability and commitment to the good of patients, caregivers, and families dealing with bone marrow failure diseases
- Respect for the worth and dignity of all individuals
- Dedication to inclusiveness and diversity
- Commitment to transparency, integrity, and honesty
- Responsible stewardship of resources

2014 FINANCIAL HIGHLIGHTS

Revenue

- Unrestricted Individual Donations
- Unrestricted Donations from Corporations, Nonprofit Organizations, and Community Foundations
- Grant and Donations Restricted for Medical Symposiums and Professional Education
- Grant and Donations Restricted for Research and Scholarship
- Grants and Donations Restricted for Clinical Research Consortium
- Grants and Donations Restricted for Patient Programs and Conferences
- Miscellaneous and Interest

Expenses

- Patient Education and Support
- Professional Education
- Medical Research
- Clinical Research Consortium
- Awareness
- Scholarship
- Management/General
- Fundraising

AA&MDSIF received Charity Navigator’s 4-Star rating for the tenth consecutive year, achieved by only the top 1% of the charities in the United States. The Guidestar Gold Level designation is the highest rating a nonprofit organization can receive for mission, governance, and transparency to donors.
Medical Advisory Board
Chair, Richard Stone, MD
Dana-Farber Cancer Center
Co-Chair, Mikkael Sekeres, MD, MS
Cleveland Clinic Taussig Cancer Center
Pamela Becker, MD, PhD
University of Washington School of Medicine
Monica Bessler, MD, PhD
Children’s Hospital of Philadelphia
Carlos deCastro, III, MD
Duke University Medical Center
H. Joachim Deeg, MD
Fred Hutchinson Cancer Research Center
Amy DeZern, MD, MHS
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Benjamin Ebert, MD, PhD
Dana-Farber/Harvard Cancer Center
Guillermo Garcia-Manero, MD
MD Anderson Center
Aristoteles Giagounidis, MD, PhD
Marien hosp ital Dusseldorf, Germany
Steven Gore, MD
Yale School of Medicine
Timothy Graubert, MD
MGH Cancer Center
Alan List, MD
H. Lee Moffitt Cancer Center and Research Institute
Jaroslaw Maciejewski, MD, PhD
Cleveland Clinic Taussig Cancer Center
David Margolis, MD
Medical College of Wisconsin
Judith Marsh, MD
Kings College Hospital
Stephen Nimer, MD
Sylvester Comprehensive Cancer Center, University of Miami
Olatoyosi Odenike, MD
University of Chicago
Ronald Paquette, MD
UCLA Medical Center
Gail Roboz, MD
Weill Medical College of Cornell University
Valeria Santini, MD
University of Florence
B. Douglas Smith, MD
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins
Neal Young, MD
National Institutes of Health

Program Partners
National Heart, Lung, and Blood Institute of the National Institutes of Health
Office of Rare Diseases of the National Institutes of Health
National Organization for Rare Diseases
PNH Research and Support Foundation

Educational Partners
Alabama State Nurses Association
American Academy of Nurse Practitioners
Association of Oncology Social Workers
Cancer Treatment Centers of America
Children’s Hospital of Philadelphia
Cleveland Clinic Taussig Cancer Institute
Delete Blood Cancer
Healio.com
Medical Education Resources
MPN Research Foundation
National Association of Social Workers
Oncology Nursing Society
Primary Care Network
Penn State Hershey College of Medicine
Robert H. Lurie Comprehensive Cancer Center at Northwestern University
Sidney Kimmel Comprehensive Cancer Center/John Hopkins Hospital
Sylvester Comprehensive Cancer Center at University of Miami
University of Florida
University of Illinois at Chicago
University of Nebraska Medical Center
University of Pennsylvania
Washington University in St. Louis School of Medicine

MDS Clinical Research Consortium Partners
Cleveland Clinic Taussig Cancer Institute
Dana-Farber Cancer Institute
MD Anderson Cancer Center
H. Lee Moffitt Cancer Center and Research Institute
Weill Medical College of Cornell University
Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

Patient Education Council
Chair, David Margolis, MD
David J. Araten, MD
Eyal Attar, MD
Maria Baer, MD
Robin Brannon
Susan Carson, RN, MSN, CPNP
Joanna Myers Casale, RD, CSO, LDN
Kenneth Cooke, MD
Amanda Foisy
Ilene Galinsky, MSN, APRN-BC
Norma Good
Steven Gore, MD
Lisa Gruber
Eric Hodies
Paige Jamieson
Joan Latsko, MSN, CRNP, OCN, AOCNP
Shyamala Navada, MD, MSCR
Rhachael Otto
Lynda Payne
Olga Nunez Rios RN, BSN
Larry Sauger
Isabel Schuermeyer, MD
David Steensma, MD
Valerie Sun
Jim Thomas
Melissa Tighe
Barbara Weinstein, RN, BSN
People who DISCOVER

2014 AA&MDSIF Grant Recipients

For 25 years, AA&MDSIF has provided research grants totaling over $4 million to an international group of more than 67 researchers to help advance the understanding and treatment of aplastic anemia, myelodysplastic syndromes (MDS), and paroxysmal nocturnal hemoglobinuria (PNH). These two-year grants have helped bring forth new insights into the causes and therapeutic approaches for these diseases. These profiles present the 2014 group of grantees and a summary of their grant-funded research projects.

Clonal hematopoiesis and autonomous lymphocyte expansion in acquired aplastic anemia

Daria Babushok, MD, PhD
Fellow in Hematology/Oncology
Hospital of the University of Pennsylvania

Funded by: Torry Yahn, Sam Jordan and Stephen and Joanna Janowiak Research Funds

Improving the self-renewal capability of stem cells derived from bone marrow failure patients

Luis Batista, PhD
Assistant Professor of Medicine Hematology
Assistant Professor of Developmental Biology
Washington University in St. Louis

Funded by: Bradley Richard Research Fund and Research is Hope Fund

The role of spliceosome in regulating DNA methylation in myelodysplastic syndrome

Rosannah Cameron, PhD
Research Fellow
Department of Developmental & Molecular Biology
Albert Einstein College of Medicine

Funded by: Lindsay Minelli Research Fund and the Research is Hope Fund

Phenotypic and molecular characterization of osteolineage cells in patients with myelodysplastic syndrome

Youmna Kfoury, PhD
Research Fellow
Massachusetts General Hospital, Center for Regenerative Medicine

Funded by: Lisa Lancaster Research Fund

Small peptide C3-inhibitors for the treatment of paroxysmal nocturnal hemoglobinuria: moving towards the bedside

Patrizia Ricci, PhD
Department of Clinical Medicine and Surgery
University of Naples, Italy

Funded by: PNH Research and Support Foundation

Discovery of small molecule complement inhibitors as the treatment for PNH

Chao-Yie Yang, PhD
Research Assistant Professor
University of Michigan

Funded by: PNH Research and Support Foundation
Doris Moreland Creates Research Fund to Honor Her Husband and Help Future Patients

Chicago area residents Doris Moreland and her husband, Jim, had a strong belief in the expression that ‘to whom much is given, much is expected.’ More than ten years after Jim’s death from aplastic anemia, Doris has made a special gift to honor him and promote bone marrow failure disease research by establishing the James D. and Doris N. Moreland Research Fund. The fund will provide a two-year grant to a researcher studying bone marrow failure disease, with a preference given to research on aplastic anemia.

“I was inspired to contribute to your organization because of the many difficult days my husband had and the realization of the impact blood diseases had on his family,” says Doris. “Jim had two cousins on his mother’s side that had similar blood diseases.”

Jim was diagnosed in April 1999. He and Doris made a number of visits to the Mayo Clinic and he had nearly 100 transfusions during his three-year fight with aplastic anemia. “His treatment was very much hit and miss – not coordinated,” says Doris. “I learned how important it is to try and get the very, very best medical help possible.”

“He was a strong person - pleasant and optimistic - very persistent. He was a very well-rounded person who lived to golf,” says Doris, who lives in Willowbrook, Illinois in the same house she and Jim had built in 1956. Jim started their neighborhood community association, was a Boy Scout leader, and served on the School Board.

It was Jim who discovered AA&MDSIF. “Jim always looked forward to your mailings and newsletters,” says Doris. “They gave him a lot of encouragement.”

Doris, a thyroid cancer survivor, is nearly 90 years old. Her sister is 101 years old, so longevity runs in the family. “I keep busy,” she says. “I spend an awful lot of time reading. I inherited my mother’s green thumb and have a forest of plants and a ten-year old unproductive avocado tree!”

AA&MDSIF Grantee Helps Discover Genetic Origins of MDS

Eirini Papapetrou, MD, PhD, and her colleagues at Icahn School of Medicine at Mount Sinai have taken mature blood cells from MDS patients and reprogrammed them back into stem cells to study the genetic origins of MDS.

“This work sheds new light on how blood cancer develops and also provides a new approach that can be used to study chromosomal deletions associated with a variety of human cancers, neurological and developmental diseases,” said Dr. Papapetrou.

Learn more about this promising new approach which is partially funded by a grant from AA&MDSIF at www.bit.ly/MDSgenetics.
People who make a DIFFERENCE

2014 LEADERSHIP AWARD RECIPIENTS

Sally and Manuel Debono and Dr. Alan List are recipients of the 2014 Leadership in Philanthropy and Leadership in Science awards.

Sally and Manuel Debono were selected to receive the Leadership in Philanthropy Award for their continued and consistent generous financial support of AA&MDSIF programs and services.

In 1984, their son, Matthew Debono, was diagnosed with severe aplastic anemia. Matthew was a cross-country runner who handled his disease, according to his parents, “with the same determination that he used to finish his races.” Diagnosed early in his freshman year at Wabash College in Indiana, Matthew regretted not being able to receive a college education. He and his brother conceived of a scholarship to help students who were similarly challenged by bone marrow failure disease.

Following his death, the family established the Matthew Debono Scholarship Fund. Over 25 years, 35 students received awards. The Debono family later established the scholarship fund with AA&MDSIF, and since 2012, an additional 61 scholarships have been awarded, bringing the total number of Debono scholarships now to 96.

Alan List, MD has been selected to receive the Leadership in Science Award. Recipients of this award are recognized for their contributions to the fields of bone marrow failure disease treatment and/or research. Nominees are considered for their impact on patients and families affected by aplastic anemia, MDS, and PNH, and/or their contributions through research to increasing knowledge and understanding about these diseases. Additional consideration is given to those who have demonstrated a commitment to AA&MDSIF.

As President and Chief Executive Officer of Moffitt Cancer Center, Dr. List is internationally recognized for his many contributions in the development of novel, more effective treatment strategies for myelodysplastic syndromes (MDS) and acute myeloid leukemia (AML). His pioneering work led to the development of lenalidomide (Revlimid®) from the laboratory to clinical trials, which went on to receive fast-track designation from the U.S. Food and Drug Administration and approval for the treatment of patients with MDS and multiple myeloma. This work transformed the natural history of MDS from a premalignant condition that progressed to malignancy requiring aggressive treatment to a condition managed in the outpatient setting with oral agents.

A member of the AA&MDSIF Medical Advisory Board, he is the author of more than nearly 300 peer-reviewed articles and the Clinician’s Manual on Myelodysplastic Syndromes (2008). He is an active member of the American Society of Clinical Oncology, American Society of Hematology, American Association for Cancer Research, International Society for Experimental Hematology, JP McCarthy Foundation Medical Advisory Committee, and the Southwestern Oncology Group. Dr. List is also a frequent presenter at AA&MDSIF conferences and appears on AA&MDSIF webinars.
COMMUNITIES OF HOPE

AA&MDSIF continues to build Communities of Hope – volunteer led, community-based support groups that connect patients and families. Communities of Hope provide a local resource for support, information exchange, and education, and engage volunteers to create awareness and encourage advocacy.

As of 2014, 14 Communities of Hope operate around the United States and eight more are in development.

- Phoenix, Arizona
- San Francisco Bay Area, California (MDS)
- Middletown, Connecticut
- Orlando, Florida
- Tampa, Florida
- Atlanta, Georgia
- Indianapolis, Indiana
- Chicago, Illinois (MDS)
- Boston, Massachusetts
- Asheville/Henderson, North Carolina
- Central New Jersey
- New York, New York
- Houston, Texas
- Milwaukee, Wisconsin

Get Social!

In our social media communities, patients, families, healthcare providers, and friends learn the latest in bone marrow failure disease research, read about upcoming events, share personal stories, and connect with fellow patients and families.

2014 Social Media Snapshot

- More than 8,900 likes
- More than 660 followers
- Over 32,000 views

facebook.com/aamds

twitter.com/aamdsif

youtube.com/aamdsif

Support Connection

The Support Connection is a national network of volunteers, including patients, caregivers, and family members, who offer comfort and support to others. One-to-one support sessions take place over the phone and via email with AA&MDSIF trained volunteers who share personal experiences, coping strategies, problem solving skills, and other resources.
Volunteering for AA&MDSIF is an important way to get involved and give back. Our dedicated volunteers made significant contributions in 2014!

More than 400 volunteers supported AA&MDSIF fundraising and awareness events across the United States in 2014, raising over $287,000 through numerous activities and events.

Snapshot of our 2014 volunteer activities:

55+ fundraising/awareness events
- 26+ new fundraising/awareness events
- 230+ volunteers helping at all events
- 26 grassroots fundraisers
- 18 new grassroots fundraisers
- 9 awareness-only events

8 walks raising over $181,000
- 4 new walks
- 1,090 walkers
- 84 walk teams
- 155+ volunteers
- 3 5K runs

Over $287,000 raised from all events
- 18 events raised $1,000+
- 10 events raised $5,000+
- 6 events raised $10,000+
- 6 events raised $25,000+
- 4 events raised over $30,000

Sampling of 2014 events:

Hope, Steps & A Cure Walks: 8 walks raised over $181,000:
- Phoenix, Arizona *
- Houston, Texas
- Los Angeles, California
- Milwaukee, Wisconsin
- South River, New Jersey *
- New Philadelphia, Ohio *
- New York, New York (partnership with PNH Research and Support Foundation)
- Spokane, Washington *

*new walks

Annual events
- Mom Prom
- Chips for a Cure
- Judy Joyce Memorial Golf Tournament
- 5 Mile Walk
- Wing Fling
- sMAC Down Macaroni and Cheese Cookoff
- Rachel’s Rally for Recovery

Other events
- Art Show
- Pros vs. Heroes Flag Football Game
- Team Julia’s Wings at the 5K Pumpkin Run
- T-Shirt Fundraiser
- Groupon Coupon
- Denim Day at work
- #GivingTuesday

Awareness Week events
- Facebook posts had 716 likes, 220 shares, and 45 comments during Awareness Week
- Bone marrow and blood drives
The MDS Clinical Research Consortium (MDS-CRC) is dedicated to improving care for MDS patients through state-of-the-art collaborative clinical research. It combines the expertise of many leading MDS researchers with the capacity of their world-class institutions to share data and advance research.

This unique research consortium is funded by the Edward P. Evans Foundation. Participating institutions include Cleveland Clinic Taussig Cancer Institute, Dana-Farber Cancer Institute, MD Anderson Cancer Center, H. Lee Moffitt Cancer Center and Research Institute, Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins, and Weill Medical College of Cornell University. The MDS-CRC is administered through AA&MDSIF, and the data core and research coordination efforts are housed at the Cleveland Clinic.

The consortium advances MDS clinical research in multiple ways, through an approach known as clinical trial acceleration. In short, clinical trial acceleration makes it possible to enroll patients in trials more rapidly from multiple research sites. With rare diseases like MDS, this is especially important since even in major medical centers, it’s difficult to find enough patients with similar enough conditions to enroll in clinical trials within a short period of time. Principal investigators in the consortium frequently work with additional researchers in their institutions and collaborate with other institutions to conduct research and train Edward P. Evans Fellows who work alongside the principal investigators.

Along with accelerating enrollment, the MDS-CRC has compiled the largest database in the U.S. of MDS patients treated with hypomethylating agents. The database is available for consortium researchers to draw from for conducting retrospective studies that can be rapidly executed since the records already exist.
People who EDUCATE

AA&MDSIF reached thousands of health professionals in 2014 with educational programs and resources designed to help them provide optimal care for bone marrow failure disease patients.

Professional Symposia

INTERNATIONAL BONE MARROW FAILURE DISEASE SCIENTIFIC SYMPOSIUM 2014
Building a Collaborative Research Community That Saves Lives

The AA&MDSIF 4th International Bone Marrow Failure Disease Scientific Symposium was held in March 2014 in Rockville, Maryland. This biennial symposium brought together 175 researchers from all over the world to share the latest research, best practices in clinical care, and important areas to focus future research efforts in bone marrow failure disease. Results of the symposium were reported to patients in recorded interviews with several of the symposium speakers and a written summary of all presentations.

Satellite Symposia were presented by AA&MDSIF at the annual meetings of the Oncology Nursing Society in May and the American Society of Hematology in December.

AA&MDSIF presented three Regional Bone Marrow Failure Disease Symposia in partnership with Northwestern University in Chicago, Penn State College of Medicine in Hershey, PA, and Washington University in St. Louis.

In-Person Programs

AA&MDSIF continued the MDS/MPN Rounds program in Chicago in partnership with the MPN Research Foundation and five major medical institutions. Participants share best practices and learn about new therapies, clinical trials, and advances in the management of MDS and myeloproliferative neoplasms (MPN) through interactive case studies presented by experts in the greater Chicago area.

Online Instruction

In conjunction with the University of Florida, AA&MDSIF produced Treatment Decision-Making Through the Spectrum of MDS, a series of continuing education programs featuring interviews with MDS patients and vignettes of their interaction with a doctor and nurse to demonstrate communication about diagnosis and treatment. These programs reach a broad range of health professionals on the Healio.com Education Lab website.

Why is this education such an important part of the AA&MDSIF mission?

“I feel the ability of the physicians, PAs, and nurses to communicate effectively is a vitally important component to good medical care. We need to feel comfortable asking questions. The quality of this communication is essential to a feeling of confidence in your team and your critical health progress.”

-- AA&MDSIF patient
Web Site

At www.AAMDS.org, visitors can:

- Access information about patient in-person events and online services
- Watch the webinars, interviews with experts, and interactive learning modules in the Online Learning Center
- Learn about managing daily life and finding support
- Read Stories of Hope – inspiring stories from patients about living with aplastic anemia, MDS, or PNH
- Find summaries of recent research
- Connect with others through links our social media channels -- all gathered in one place.
- Donate to help sustain AA&MDSIF patient services, and support research or get involved with raising awareness.

Electronic Resources

www.AAMDS.org/Learn

The Online Learning Center’s programs are available to patients and families anytime and anywhere, providing easy access to more than 100 video presentations (webinars, webcasts, prerecorded interviews, and interactive learning modules). Participants can stop, review, or repeat the presentations, as well as share with other family members involved in the patient’s care. In 2014, more than 1,300 individuals registered for educational webinars.

Treatment Tracker App

The Treatment Tracker enables patients to track treatment, document and display in graph form any symptom/side effects experienced, as well as create a record and monitor lab results. It is also available in spreadsheet and print formats.

What Is MDS? iPad App

Patients and their families can use the iPad app to learn about MDS in several ways:

- Watch the What is MDS? video
- Read, listen, or view the FAQ section
- Request educational materials and/or read the materials included in the app
People who
INFORM

AA&MDSIF Newsletters

Electronic

Connect

The twice-monthly Connect is a free electronic newsletter packed with information covering all AA&MDSIF programs. Emphasis is on time-sensitive information about our patient conferences, Online Learning Center, plus awareness and fundraising events. The Connect also contains advice for patients, relevant news from the research and treatment fields, inspiring Stories of Hope features, and much more. As a convenient way to keep up with the latest news from AA&MDSIF, the Connect brings it all together, twice a month.

Healthcare Professionals Connection

This quarterly electronic newsletter is distributed to more than 25,000 physicians, nurses, researchers, and other healthcare professional who work with patients having bone marrow failure diseases. It presents articles on practical treatment, patient communication, and current research. The Healthcare Professionals Connection also includes information on AA&MDSIF resources for patients, and live and online continuing education (CME) opportunities.

Research Connection

This monthly electronic newsletter focuses on bone marrow failure disease research in one convenient source. Readers find information and interviews from leading medical researchers, stories from patients who have been helped by research, highlights of the research supported by AA&MDSIF and research presented at major scientific conferences. The Research Connection also calls attention to the webinars and webcasts found in the AA&MDSIF Online Learning Center.

Aplastic Anemia and PNH Connection

These two quarterly electronic newsletters connect readers with recently posted content on www.AAMDS.org. Readers receive up-to-date information on all aspects of treating, managing, and living well with aplastic anemia or paroxysmal nocturnal hemoglobinuria (PNH), plus information on the broad array of AA&MDSIF programs and services.

Print

MDS Connection

Now in its fifth year, the MDS Connection is an important resource for MDS patients. Issued six times per year, each issue includes interviews with a broad range of experts, positive stories about MDS patients managing their disease, and information about AA&MDSIF support services for patients and caregivers. The MDS Connection has a circulation over 13,000 and is also distributed to physician’s offices, at conferences, and via patient information packets.
**Patient Guides**

Our five free print patient guides are between 20 and 36 pages, containing the information and detail patients and families want. All content is reviewed by top experts and is updated with each new edition.

- **Your Guide to Aplastic Anemia**
- **Your Guide to Myelodysplastic Syndromes (MDS)**
- **Your Guide to Understanding MDS Drug Therapies**
- **Your Guide to Paroxysmal Nocturnal Hemoglobinuria (PNH)**
- **Your Guide to Living Well With Bone Marrow Failure Diseases**

**Research Summaries**

AA&MDSIF Research Summaries provide plain language explanations of significant research in bone marrow failure disease research and treatment.

Members of the AA&MDSIF Medical Advisory Board identify the relevant scientific studies presented at major conferences, including the American Society of Hematology (ASH), American Society of Clinical Oncology (ASCO), European Hematology Association (EHA), and other sources, including National Heart, Lung and Blood Institute (NHLBI), National Cancer Institute (NCI), MDS Clinical Research Consortium, and other notable resources. In 2014, Research Summaries were available in print and online.

**AA&MDSIF Patient and Family Conferences**

Since 2011, AA&MDSIF has offered six day-long conferences around the country to provide patients and families with answers from medical experts, to find support from other patients and caregivers, and to gain a sense of optimism and hope.

In 2014, there were more than 700 registrants for conferences in Los Angeles, Philadelphia, Louisville, Detroit, New Orleans, and Miami. Live international webcasts of conference sessions in 2014 enabled more than 300 registrants from 30 countries to join the sessions.

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“Having both of my senior parents diagnosed with bone marrow failure disease, I attended the AA&MDSIF conference with a mission in my heart—seeking understanding of this disease, how it progresses, and all of the possible treatments. I left that day with all of those questions answered. I found encouragement, expert information, personal stories, and an opportunity for on-going connections and help.”

-- Jennifer
Patient Profile
Lorenzo Williams
A survivor now helps others

“In August 1995, my family and I moved from Memphis, Tennessee to the small town of Tifton, Georgia for a job promotion, which I was very excited about. After working ten-hour days in planning meetings, I was always extremely tired at the end of the day. I finally saw a doctor, and he did some lab work. He referred me to a hematologist/oncologist who admitted me to the hospital that same day. I had a white blood cell count of 1.5, a hemoglobin count of 6.5, and a platelet count of 9,000. He did a bone marrow biopsy and found that I had severe aplastic anemia.

I received this diagnosis on October 3, 1995, one day before my 39th birthday. All of my family members were tested to see if they were possible bone marrow donors, but there was no match. In 1995, there was no Google or Web MD to find any information about my disease. When I finally found some information in a medical journal, it said aplastic anemia was a disease with a life expectancy of less than five years.

We organized several bone marrow drives, but still no match was found for me. I had two rounds of horse ATG and we waited to see how I would respond. While I will never be cured of my disease, I have learned to live with it and not let it determine how I live my life.

About six months after finding out about my illness, my wife became ill with multiple myeloma. The roles were reversed from her being my caregiver to me being her caregiver.

During this time I learned the power of a support group. We would drive three hours each month from Tifton to Atlanta to meet with people with her disease. We were able to share our stories and talk with others who were going through some of the same things we were experiencing.

In 2004 my wife lost her battle with cancer. I started attending a bereavement support group. In 2006, I started dating again and married a wonderful friend in 2008 who helped me to understand that you can pick yourself up and move on with your life. We both retired and moved to Atlanta, Georgia in 2009. My wife and I started the Atlanta Community of Hope for aplastic anemia, MDS, and PNH patients and families in metro Atlanta. Support groups have been a source of great strength for me in my life. I feel the least I can do is help someone else by sharing what I have experienced on my personal journey with this disease.”

Patient Profile
Ellen O. Kalinosky

Her doctor’s advice – “You have only one thing to do. And that is hope. Because hope only goes one way and that way is forward.”

Joe and I were 25 years old in spring 1983. We moved quickly from a blind date to wanting a life together. Pre-marital blood work uncovered abnormally low blood counts. In between bridal showers, wedding, and honeymoon, we were sitting in doctors’ offices with an unclear picture of what was wrong.

Writing to dozens of specialists for advice, we were directed to Duke University Medical Center. There, I was diagnosed with aplastic anemia and paroxysmal nocturnal hemoglobinuria (PNH). A new clinical trial of ATG (antithymocyte globulin) and the connection with the newly formed AA&MDSIF gave us hope and trusted sources for treatment, information, and support. Slowly, my body responded to treatment, and we moved on.

We blinked through a rich life of marriage, birth of our daughter, and our careers. A small bruise appeared in spring 2013 to remind me of days gone by. Tests uncovered abnormalities again. Almost 30 years to the day sitting in a doctor’s office, we were told that I had myelodysplastic syndromes (MDS). For the second time, we found a trusted doctor at Memorial Sloan Kettering in NYC to implement the plan of azacitidine (Vidaza®) followed by a stem cell transplant. I received the gift of life from my brother, Neal, on January 25, 2014.

Visit www.AAMDS.org/ellen to read Ellen’s complete story of three decades with bone marrow failure diseases.
Matthew Debono was diagnosed with aplastic anemia when he was a freshman at Wabash College in Indiana. He was unable to complete his college education, and his family established the Matthew Debono Memorial Scholarship Fund in 1986. Four years ago, the Debono family partnered with AA&MDSIF to expand Matt’s legacy through additional scholarships.

Thanks to the Debono family and friends, students from 12 states were awarded scholarships ranging from $1,000 to $2,000 in the 2014-2015 academic year.

Scholarship Winners in Their Own Words

“College feels so much more rewarding after going through treatment. Otherwise, I might have taken it for granted. During treatment, all I wanted to do was go to school. Now that I am in school, I do not want to miss a beat. I am much more aware of everything I have now and so grateful for everything.”

— Kayla Iles

“At the age of 5, I was diagnosed with very severe aplastic anemia. After 27 months of immune suppression chemotherapy, dozens of biopsies, hundreds of transfusions, I finally went into remission (without a transplant). I’m inspired by my iPhone screensaver: a collage of four of my friends and heroes - Talia, Zach, Bella and Lane – with the words, ‘They wouldn’t waste a second.’ If they had lived, they wouldn’t waste a second. So I shouldn’t, either.”

— Kinsey Morrison

2014 Debono Scholarship Winners

Timberly Bowie
Pocatello, Idaho
Utah State University

Tashia Navarro
Myrtle Creek, Oregon
Oregon State University

Christina Chen
Harahan, Louisiana
University of Chicago Pritzker School of Medicine

Christopher Nein
Chesapeake, Virginia
Eastern Virginia Medical School

Thomas Howlett
Plano, Texas
University of Texas-Dallas

Nicholas Panarello
Barrington, Rhode Island
Northeastern University

Kayla Iles
Elsmere, Kentucky
Christ College of Nursing & Health Sciences

Nicholas Pipitone
Harrison, New York
SUNY - University at Albany

Rasha Iqbal
Gaithersburg, Maryland
Montgomery County College

Alexa Puppo
Fargo, North Dakota
Minnesota State University – Moorhead

Annette Lysan
Wakefield, Massachusetts
Curry College

Caitlyn Ulinski
Romeo, Michigan
Kettering University

Kinsey Morrison
Goshen, Kentucky
Stanford University

Kimberly Woudenberg
Carbondale, Illinois
Southern Illinois University

People who are the FUTURE
Scholarship Recipient Profile

Christina Chen Takes Global View of the Other Side of Health Care

Christina says that when she reflects on her own experiences of getting labs drawn as an aplastic anemia patient, “It is still unbelievable to me that I am on the other side of healthcare, gloves and needle in hand.”

Christina was diagnosed with aplastic anemia in 2001 when she was nine years old in fifth grade. Her mother, who is a medical researcher, knew about Dr. Neal Young at the National Institutes of Health and brought Christina from their home in New Orleans to be treated at NIH. The young girl was treated with immunosuppressive therapy in a clinical trial and after three months, she achieved full recovery.

From NIH Patient to NIH Staff

The three-time scholarship recipient has now come full circle. In 2014, Christina spent a year as a medical researcher in a hematology lab at the National Institutes of Health performing data analysis on clinical trials, working for the same doctor, Dr. Young, who saved her life. During her year at NIH, she even visited some aplastic anemia patients in their clinic and shared her experiences with them.

Twenty-three year old Christina has just completed her first year of medical school at the University of Chicago, the same place where she received her undergraduate degree in 2013. “I have had an extremely busy first year of medical school,” she says. “I was placed into a longitudinal preceptorship (mentoring experience) in an oncology clinic examining breast and gynecological cancers. In addition to her studies, she also started volunteering in the phlebotomy lab at the Community Health Clinic, which is a student-run free clinic for a large population of underinsured and uninsured patients in Chicago.

Interest in Global Health Settings

She is interested in helping to bridge the healthcare gap in third-world countries.

“Health disparities and the unaffordability of healthcare have grown as really significant issues I want to address during my medical education. I plan to continue volunteering in free clinics to help patients who fall through the gaps of our healthcare system and figure out some solutions to the inequalities of health outcomes among different populations,” says Chen.

While she was an undergraduate, Christina was able to study abroad in South Africa and Taiwan. This summer she is doing a research project in Nigeria interviewing mothers about their knowledge of sickle cell disease and what barriers they have to getting their children screened. She will also take one week at the end of the summer to assist in cervical cancer screenings in Peru.

Advice and Gratitude

Christina’s career aspirations are to become a practicing physician involved in clinical trial work. She feels she has grown a lot from her experiences as an aplastic anemia patient, learning how to stay positive. “My advice for other patients is to enjoy life as much as you can. Having that spirit helps you along.” She is grateful to the Debono family for relieving some of her educational costs and making it possible for her to study abroad. “The Debono scholarships have meant a great deal to me in knowing I have the support of patients and their families in pursuing my aspirations to be a physician,” says Christina. “They act as a reminder of my own experiences with aplastic anemia and how stressful a disease is for the entire family, which I take with me when I interact with patients in the clinics.”
Our thanks to all individuals, corporations, foundations, and organizations for their contributions to fund AA&MDSIF’s programs and services during 2014. We honor all of our generous supporters, with special recognition in this annual report to those who have donated $500 or more during 2014.

Every effort has been made to accurately acknowledge all contributors who gave $500 or more cumulatively between January 1, 2014 and December 31, 2014. If you see an error or omission, please contact Michael Breuer at (301) 279-7202 x111 or email breuer@aamds.org. We apologize for any unintended errors. We are very grateful to each of you for your generosity.

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-- The Rivera family
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