



Aplastic Anemia and MDS International Foundation

# 2016 ANNUAL REPORT



## THE MISSION

AAMDSIF focuses on bone marrow failure diseases, educating and connecting patients, families and health professionals worldwide. It also promotes and invests in collaborative clinical research to study and find cures for aplastic anemia, MDS and PNH.

## THE VISION

We envision the day when bone marrow failure no longer claims lives. Until then, we will continue to make progress by evolving our programs and services to meet the needs of patients who rely on us and health professionals who turn to us as a trusted partner.

*For 12 consecutive years, AAMDSIF has earned the coveted 4-star rating from leading independent charity evaluator, Charity Navigator.*

# IMPACT

made in  
2016



**61,576** unique page  
views by month



by  
**35,138** users



**65,745**  
newsletter  
distribution



**44,200**  
views of Online  
Academy



More than **17,000** views of education videos

**500**



patient information booklet requests

**700** virtual and in  
person attendees for  
**6 Regional Patient and  
Family Conferences**



As 12/16/2016

## The MDS Clinical Research Consortium (CRC)

Established in 2012 with support from The Edward P. Evans Foundation

The MDS Clinical Research Consortium (CRC) is an innovative collaboration of six of the nation's leading academic research institutions administered by the Foundation and designed to accelerate scientific progress for MDS patients.

Members include the 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, and Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins. Investigators at these prestigious institutes lead the nation's highest-quality clinical and database studies.

Thanks to the \$16 million of seed money provided by the Edward P. Evans Foundation, CRC members are sharing patient care and research expertise, financial resources, data and tools. As of last year, the CRC opened both Phase I and Phase II clinical trials and built a unique database of over 2,500 records, including tissue samples of patients treated with hypomethylating agents.





## The Scientific Research Grants Program

### Continuing Distribution of Funds to Support Select Studies

Over 25 years, we have provided investigators with financial support for research that leads to new insights into the causes of bone marrow failure and the development of new therapeutic approaches.

The Foundation's Medical Advisory Board reviews the applications and awards grants based on the scientific quality of the research plan, the relevance of the proposed research to the Foundation's goals, the applicant's qualifications and the quality of the research institution and facility where the study will be conducted. In 2016, three grantees were awarded \$30,000 each for their respective studies on aplastic anemia, MDS and PNH.

## 2016 GRANT RECIPIENTS

- **Aplastic Anemia:**  
Simona Pagliuca  
Arthur Kunofsky  
Research Fund
- **MDS:** Akihide Yoshimi  
Shirley and James  
O'Brien Research Fund
- **Aplastic Anemia:**  
Kate McNamara  
The Julia Malsin  
Research Fund
- **MDS:** Tushar Bhagat  
Carol and Peter Stewart  
Research Fund
- **PNH:** Alina Dulau Florea  
Patricia and Vincent  
Geczik Legacy Fund

## The Patient Advisory Committee for Clinical Trials (PACCT+) Established in 2015 with support from the Patient-Centered Outcomes Research Institute (PCORI)

This ground-breaking group of specially-trained bone marrow failure patients is available to add the patient's unique voice and experience to the development of clinical trial protocols and research studies conducted by both the pharmaceutical industry and academic researchers.



PACCT+ provides non-binding patient-centered feedback that includes message development for patients which emphasizes the importance of scientific clinical research. All committee members are volunteers who have been specifically educated by the Foundation on clinical trial protocols.

# COMMUNITY EVENTS



AA•MDS INTERNATIONAL FOUNDATION

Everyone touched by bone marrow failure disease hopes for a cure. March for Marrow walk and run events help us get closer to that goal. They are designed to ensure that anyone, anywhere can participate – either in person or virtually.

In 2016, nationwide community events like barbeques and golf tournaments combined with our 11 Marches for Marrow to raise more than **\$420,000**. We thank our generous and dedicated group of more than 2,000 supporters and volunteers for their efforts to raise awareness for bone marrow failure diseases. A few highlights include:



## **March for Marrow DC**

The Foundation launched its first national walk in the nation's capital that created unprecedented awareness for bone marrow failure disease and raised over **\$250,000.00** for research and patient education.

## **March for Marrow PNH Walks in New York and Ohio**

Over 200 participants raised more than **\$28,000.00** for awareness, research and education about PNH.





### March for Marrow Houston

In partnership with the University of Houston and Frontier Fiesta, the Foundation hosted 250 patients, families, friends and students, raising over **\$35,000.00**.



### March for Marrow LA

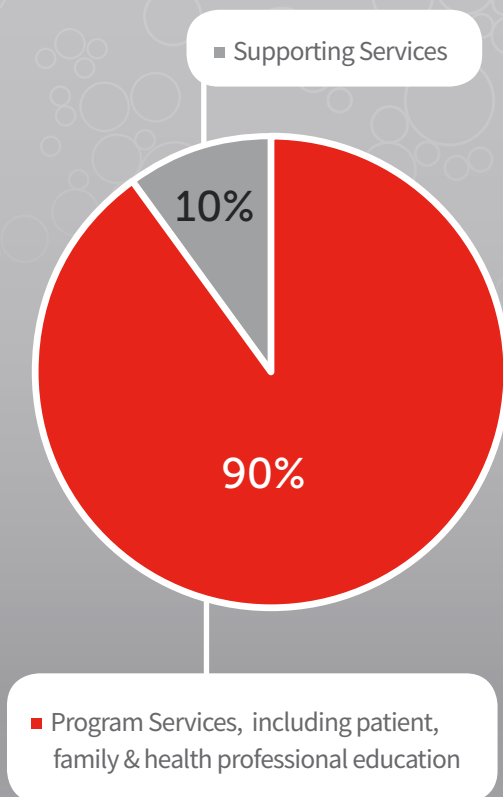
More than 200 Long Beach and Los Angeles residents raised more than **\$46,000.00** for awareness, research and education.

Other community fundraisers included t-shirt sales and annual festivities, such as the Halloween Benefit Bash, sMac Down and Wing Fling, to name just a few of our volunteers' creative events.

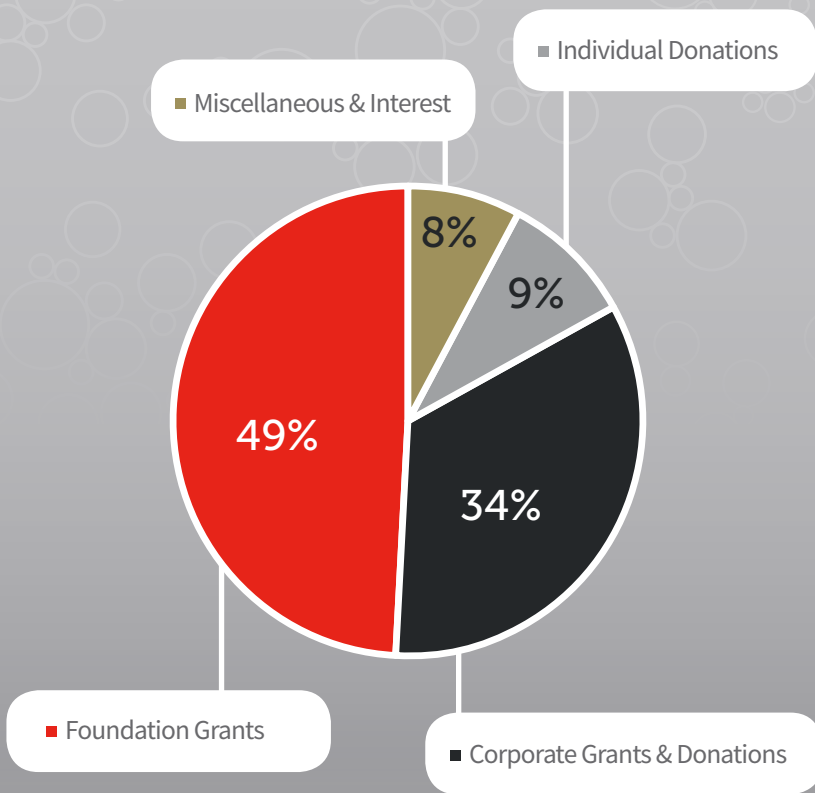


Additional March for Marrow events took place in **Williamsburg** (pictured), **Miami**, **East River** and **Detroit**.

## FY16 EXPENSE AUDITED



## FY16 REVENUE AUDITED





APLASTIC ANEMIA AND MDS INTERNATIONAL FOUNDATION, INC.

**Statements of Financial Position**  
**As of December 31, 2016**  
**with Summarized Financial Information for 2015**

	<b>Assets</b>	<b>2016</b>	<b>2015</b>
<b>CURRENT ASSETS</b>			
Cash and cash equivalents		\$1,581,413	\$1,460,357
Investments		2,680,166	3,861,406
Contributions and grants receivable		652,890	442,622
Prepaid expenses		310,711	225,649
Total current assets		<u>5,225,180</u>	<u>5,990,034</u>
<b>FIXED ASSETS</b>			
Property and equipment		360,519	272,668
Less: Accumulated depreciation		(238,078)	(235,566)
Net fixed assets		<u>122,441</u>	<u>37,102</u>
<b>OTHER ASSETS</b>			
Security deposits		25,783	10,541
Charitable Remainder Trust		265,238	250,224
Total other assets		<u>291,021</u>	<u>260,765</u>
<b>TOTAL ASSETS</b>		<u><b>\$5,638,642</b></u>	<u><b>\$6,287,901</b></u>
<b>Liabilities and Net Assets</b>			
<b>CURRENT LIABILITIES</b>			
Accounts payable		\$72,859	\$353,575
Accrued expenses		291,374	62,353
Grants payable		748,620	1,144,187
Total current liabilities		<u>1,112,853</u>	<u>1,560,115</u>
<b>LONG-TERM LIABILITIES</b>			
Deferred rent		\$42,939	-
Total liabilities		<u>1,155,792</u>	<u>1,560,115</u>
<b>NET ASSETS</b>			
Unrestricted:			
Undesignated		211,137	129,820
Board-designated		242,912	272,912
Total unrestricted		<u>454,049</u>	<u>402,732</u>
Temporarily restricted		4,028,801	4,325,054
Total net assets		<u>4,482,850</u>	<u>4,727,786</u>
<b>TOTAL LIABILITIES AND NET ASSETS</b>		<u><b>\$5,638,642</b></u>	<u><b>\$6,287,901</b></u>

APLASTIC ANEMIA AND MDS INTERNATIONAL FOUNDATION, INC.

**Statements of Activities and Change in Net Assets**  
**For the Year Ended December 31, 2016**  
**with Summarized Financial Information for 2015**

	<b>2016</b>		<b>2015</b>	
	<b>Unrestricted</b>	<b>Temporarily Restricted</b>	<b>Total</b>	<b>Total</b>
<b>REVENUE</b>				
Contributions and grants:				
Individuals	\$504,045	\$93,230	\$597,275	\$713,647
Corporate and other	1,766,337	511,419	2,277,756	1,189,176
Foundations	534,598	2,706,700	3,241,298	3,291,915
Special events	6,274	2,646	8,920	16,315
Trust and wills	174,614	15,014	189,628	92,309
Investment (loss) income	207,696	-	207,696	(53,113)
Contributed materials and services	68,971	-	68,971	23,859
Conference and other revenue	62,389	-	62,389	33,365
Net assets released from donor restrictions	3,625,262	(3,625,262)	-	-
Total revenue	<u>6,950,186</u>	<u>(296,253)</u>	<u>6,653,933</u>	<u>5,307,473</u>
<b>EXPENSES</b>				
Program Services	<u>6,216,903</u>	<u>-</u>	<u>6,216,903</u>	<u>5,925,293</u>
Supporting Services:				
General and Administrative	236,606	-	236,606	315,423
Fundraising	<u>445,360</u>	<u>-</u>	<u>445,360</u>	<u>444,882</u>
Total supporting services	<u>681,966</u>	<u>-</u>	<u>681,966</u>	<u>760,305</u>
Total expenses	<u>6,898,869</u>	<u>-</u>	<u>6,898,869</u>	<u>6,685,598</u>
Change in net assets	51,317	(296,253)	(244,936)	(1,378,125)
Net assets at beginning of year	<u>402,732</u>	<u>4,325,054</u>	<u>4,727,786</u>	<u>6,105,911</u>
<b>NET ASSETS AT END OF YEAR</b>	<b><u>\$454,049</u></b>	<b><u>\$4,028,801</u></b>	<b><u>\$4,482,850</u></b>	<b><u>\$4,727,786</u></b>



## Meet our Corporate and Foundation Sponsors

- 4imprint USA
- Acceleron Pharma
- Ace Hardware
- Achillion Pharmaceuticals, Inc.
- Actinium Pharmaceuticals, Inc.
- Agios Pharmaceuticals
- Akari Pharmaceuticals
- Alexion Pharmaceuticals, Inc.
- Alnylam Pharmaceuticals
- Amgen Inc.
- Apellis Pharmaceuticals
- APhA-ASP
- Asians for Miracle Marrow Matches
- Avate Apparel
- Be the Match
- Borough of South River
- Brooks
- Calibre CPA Group
- Calvert Computer Solutions
- Celgene Foundation
- Chick-fil-A
- Clark Construction
- Clif Bar
- Closets of Virginia
- Coastal Occupational Medical Group
- Consummate Capital, LLC
- CTI BioPharma group
- DKMS
- Dynamic Event Sercie
- Edward P. Evans Foundation
- Einsten Bros. Bagels
- European Homemade Provisions
- Fleet Feet Sports
- Frost Banking Investments Insurance
- Gatorade
- Gelman Rosenberg and Freedman
- Genentech
- Gilead Sciences, Inc.
- GNC
- Gold's Gym
- HEB
- Henry and Marilyn Taub Foundation
- Herman Goldman Foundation
- Hilton
- Hilton Long Beach
- Houston Astros
- Incyte Corporation



- Independence at home
- Intercontinental Hotels Group
- Jamba Juice
- James Avery Artisan Jewelry
- Jazz Pharmaceuticals
- Karyopham Therapeutics
- Keenan Associates
- Kohl's
- Langley Federal Credit Union
- Law Office of Bart S. Fisher
- LifeGift
- Marriott Family Foundation
- Mati Health Energy
- MEI Pharma
- Mia Hamm Foundation
- ML Clark Real Estate
- My Fit Foods
- National Metal Stamping
- Novartis
- Nurturing Force
- Oliver Carr Company
- Onconova Therapeutics
- P2S
- Ra Pharmaceuticals
- Rare Patient Voice, LLC
- Reich & Tang
- Ria Mar
- Road ID
- Runners High
- Seattle Genetics, Inc.
- Sentara
- Shoreline Village
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- TBS
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- The Oaks at Ojai
- The Shadden Group at Morgan Stanley Wealth Management
- United Valet Parking
- University of Texas MD Anderson Cancer Center
- Wells Fargo
- Whole Foods Long Beach
- World Class Automobiles



## **Meet Our Educational Partners**

Alabama State Nurses Association  
American Academy of Nurse Practitioners  
Be The Match  
Cleveland Clinic Taussig Cancer Institute  
Delete Blood Cancer  
The Fred Hutchinson Cancer Research Institute  
Medical College of Wisconsin  
Medical Education Resources, Inc.  
MPN Research Foundation  
National Comprehensive Cancer Network (NCCN)  
National Organization of Rare Diseases (NORD)  
Oncology Nursing Society  
Oregon Health & Science University  
Patient Access Network Foundation  
Patient-Centered Outcomes Research Institute (PCORI)  
Primary Care Network  
University of Maryland

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## **Meet MDS Clinical Research Consortium Partners**

MD Anderson Cancer Center, University of Texas  
Cleveland Clinic Taussig Cancer Institute  
Dana-Farber Cancer Institute  
Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University  
Lee Moffitt Cancer Center and Research Institute  
Weill Medical College of Cornell University

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## **Meet Our Program Partners**

The National Institutes of Health  
including The National Heart, Lung and Blood Institute and  
The Office of Rare Diseases

## Meet Our Volunteer Board of Directors

**Chairman:** Kevin Lyons-Tarr

**Vice Chairman:** Harsha Murthy

**Secretary:** Stephen King

**Treasurer:** Tony Sanfilippo

**Chief Executive Officer:** Kathleen Weis

### **Board Members:**

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Bart Fisher

James Gajewski, M.D.

Stephanie Dillon Hamm

Neil Horikoshi

Melanie Marquez

Judy Paulette

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## Meet our Medical Advisory Board

### **Co-Chair**

Richard Stone, MD

*Dana-Farber Cancer Center*

### **Co-Chair**

Mikkael Sekeres, MD, MS

*Cleveland Clinic Taussig Cancer Center*

### **Members**

Pamela Becker, MD, PhD

*University of Washington School of Medicine*

Carlos M. de Castro, III, MD

*Duke University Medical Center*



*Meet our Medical Advisory Board of Volunteer Specialists continued*

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*Fred Hutchinson Cancer Research Center*

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*Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins*

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*Cleveland Clinic Taussig Cancer Center*

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**Judith Marsh, MD**

*Kings College Hospital - London, UK*



*Meet our Medical Advisory Board of Volunteer Specialists continued*

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**B. Douglas Smith, MD**

*Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins*

**Neal Young, MD**

*National Institutes of Health*



## Meet Our Volunteer Patient Education Council

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Cory Cutler, MD

Amy DeZern, MD

Amara Foisy

Norma Good

Eric Hodies

Catherine MacClean

Lynda Payne

Olga Nunez Rios, RN, BSN

Isabel Schuermeyer, MD

Cathy Schmeiter, RD

Raoul Tibes, MD, PhD

Danielle Townsley, MD

Barbara Weinstein, RN, BSN

Ron Duncan

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## Allied Organizations

- NCCN – National Comprehensive Cancer Network
- ASH – American Society of Hematology
- ASCO – American Society of Clinical Oncology
- NORD – National Organization of Rare Diseases
- MDS Foundation
- MDS Alliance
- All CRC partners
- ONS – Oncology Nurses Society

# THE POWER OF COMMUNITY SUPPORT



The Foundation greatly appreciates the support of patients, family members and friends. Private support allows the Foundation to provide the education, information and resources to help people understand these diseases and their treatment. THANK YOU!

Gifts are received through various fundraisers, March for Marrow runs and walks, as well as gifts made in tribute, memory and honor of loved ones. Each and every gift makes a difference in the life of someone diagnosed with a bone marrow failure disease.

We are very grateful to our donors giving at the leadership level to advance our mission:

Brian and Rebekah Anderson  
Kelley Anderson  
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Phil and Jodie Bakes  
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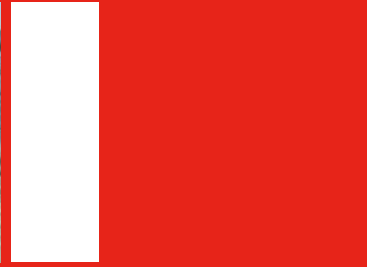
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Katie Workman  
Bruce Young  
Howard Ziff  
Andy Zinkl

AAMDSIF represents a  
**COMMUNITY**

strongly committed to finding a cure  
for bone marrow failure diseases or  
better treatments so that they are no  
longer life threatening or debilitating.

No one is immune to bone marrow  
failure, which can strike any gender  
at any age, regardless of race or  
ethnicity. Our #1 priority is having  
the greatest IMPACT on the patients  
and families we serve. Here is a small  
cross-section of them from all  
corners of the country.





Please support AAMDSIF as often  
and as generously as you can.  
Each gift makes a difference to  
someone in our community.

You can trust AAMDSIF to use your  
funds wisely – in 2016, we spent 90%  
of our resources serving patients with  
support, education and research.



AAMDSIF is a 501(c)(3) charity. Your gift is tax-deductible as  
allowed by U.S. law.



**AA•MDS**  
INTERNATIONAL FOUNDATION

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[www.aamds.org](http://www.aamds.org)