



ANNUAL REPORT

- 2019 -

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WHAT IS
MDS?

Myelodysplastic syndromes (MDS) are an often unrecognized, under-diagnosed rare group of bone marrow failure disorders, where the body no longer makes enough healthy, normal blood cells in the bone marrow. The disease is also known as a form of blood cancer.



 **THE 15TH INTERNATIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES**
COPENHAGEN, DENMARK
8-11 MAY 2019

A MESSAGE FROM OUR DIRECTORS

Tracey Iraca &
Stephen Nimer, MD



It is hard to believe that it has been 25 years since the MDS Foundation was established to promote the ongoing exchange of information relating to MDS. How far we have come!

In these 25 years we have developed a vital network of MDS Centers of Excellence; hosted 15 International Congress meetings to educate healthcare professionals on the latest scientific developments in MDS; supported young investigators with grants to further research in MDS; developed and revised the International Prognostic Scoring System to better classify and treat patients with MDS; and worked diligently to support and educate patients and their families as they travel through their MDS journey.

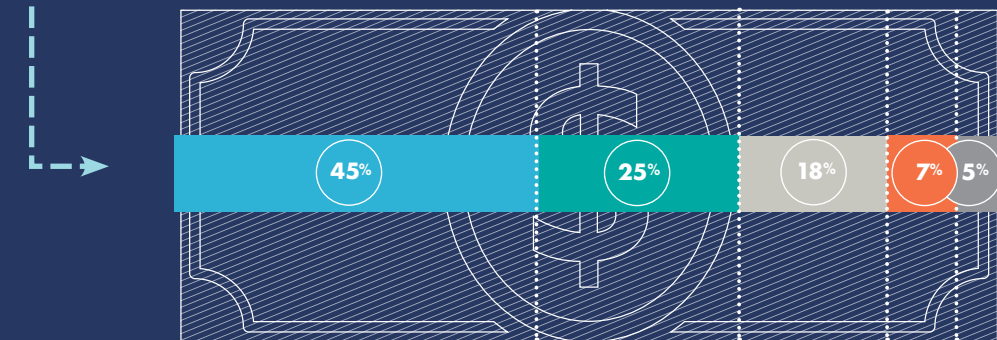
In our 2019 report, you'll see the work of a dedicated team committed to improving the lives of patients LIVING with MDS, AML, and related myeloid neoplasms. The research into MDS, AML, and MPNs has grown, with more professionals dedicated to these diseases than ever before. We continue to learn more about the biology of these diseases and to develop the tools needed to understand related diseases, including clonal hematopoiesis. We continue our efforts to prevent early stages of these diseases from developing into more serious stages and to have new therapies and more hope for patients and families battling these diseases. The strength of the MDS Foundation is made possible due to the incredible patients, caregivers, family members, healthcare providers, researchers, supporters, and partner organizations we are honored to work with every day. The MDS community is strong and growing stronger thanks to continued advances in research and treatment.

Thousands worldwide depend on the MDS Foundation for information, education and empowerment. Given the dedication and strength of our ever-growing community, we are proud to continue to lead the way and provide support for this community for years to come.


TRACEY IRACA
Executive Director


STEPHEN NIMER, MD
Board of Directors, Chairman

THE IMPACT OF YOUR DOLLAR



45% Professional Education & Training

Professional education initiatives for healthcare providers.

- International MDS Foundation Congress Events
- Regional MDS Foundation Symposia
- Annual American Society of Hematology Symposia
- Professional Learning Center with CME opportunities

25% Patient Advocacy

Support and resources for patients and caregivers.

- Patient and Caregiver Advocacy, Support and Education
- In person and online communities connecting patients, caregivers and others affected by MDS
- Regional patient forums
- Support and Educational Resources

18% Research

Research opportunities for investigators to initiate, continue or complete projects that focus on basic or clinical management into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis and treatment of the myelodysplastic syndromes.

- Young Investigator Grants
- International Working Group for the Prognosis in MDS (IWG-PM)
- MDS/MPN International Working Group (MDS/MPN IWG)

7% Fundraising

Events that focus on awareness of MDS and fundraising towards the mission of the MDS Foundation.

5% Management & General

Representing general operating expenses for directing the affairs of the MDS Foundation.

- Customer relations management
- Finance
- Human resources
- Information technology services



THE FACES OF MDS

"If you are going through this illness as a patient keep pushing forward. It is hard, painful and it can be a long recovery like mine. But you will get there."

— ASHLEY CAMARA —



ONE LIFE FOR THE TWO OF US.

THE STORY OF ASHLEY CAMARA

My story begins in Mérida, Yucatán, México, where my brother and I were born and raised. We were taught to be independent, responsible, caring, hardworking and loved spending time with friends and family. Yes, we were individuals, but deep down my brother and I were one and the same. We both shared the same passion for helping others - whether giving someone a laugh after having a bad day or lending an ear when in distress.

In November 2013, after graduating college and starting his life, my 23-year old brother suddenly fell ill and was quickly diagnosed with MDS. It was a shock, especially because we had no idea what the implications were for this disease. My family pulled together to research his condition, which only made us more concerned as we learned about the possible outcomes. Due to his already advanced condition, the only treatment for him was a stem cell transplant. Unfortunately, I was not a suitable donor, and my mother was only a half-match; but she was the best donor at that time.

The transplant was done, but due to his compromised immune system and other complications, my brother died in 2015 at the age of 24.

My crisis came in August of 2016. I woke up with feet aching so badly that I couldn't walk, and on September 1st, at age 22, I was diagnosed with MDS. As in my brother's case, a transplant was my only option for survival. Unlike my brother, however, I was fortunate enough to have several unknown, unrelated perfect matches. The doctors picked one, and I received my stem cell transplant June 27, 2017.

The recovery process wasn't easy, and I honestly don't know how I kept going, but I believe I unconsciously decided to live for my brother and for myself. He didn't have the chance to live the full life he deserved, so I was determined to live for both of us.

I am currently two years' post-transplant and enjoying every single day. I work two jobs, workout, travel, I'm independent from my family and I have been advocating for MDS awareness, AML (Acute Myeloid Leukemia) and I continue to learn more and more about these diseases. One of the events I recently participated in was the first ever MDS walk/run in Chicago. I ran a 5k. I was very proud of myself and I felt my brother running beside me the whole way.

6 WAYS YOU MADE AN IMPACT IN 2019

1 Provided Patient Education

Your support allows for live patient forum events, the development of patient support groups, and online and printed materials for those with MDS, their caregivers and those impacted by the disease.

2 Increased Patient Support

Your support allows for the Foundation to provide referrals to MDS Centers of Excellence and counseling for patients and families.

3 Provided Professional Education

Your support allows for the latest developments in MDS to be shared with healthcare providers through online and in-person events like our 2019 International Congress & ASH Symposium.

4 Awarded Research Grants

Your support allows for the distribution of Young Investigator Grants with the opportunity to initiate, continue or complete a project that focuses on either basic or clinical management into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis and treatment of the myelodysplastic syndromes. Young Investigator grants were awarded in the US and Japan in 2019.

5 Increased Awareness of MDS

Your support allows the Foundation to grow awareness and support of MDS through the expansion of our Awareness Run/Walk events, growing our communities in-person, online and through our social media channels.

6 Expanded Awareness of Clinical Trials

Your support allows the Foundation to make patients aware of new clinical trials and assist in enrollment. Our assistance in these studies leads to drug development.





CHICAGO
June 22, 2019

BOSTON
September 14, 2019

GROWING AWARENESS & MDS COMMUNITIES

The MDS Awareness Walks/Runs held in Chicago and Boston helped to spread awareness and bring attention to this disease among the physician community as well as the general public.

The walks elevated the conversation around the unmet needs of those living with MDS by bringing together the MDS and rare disease community. New connections were created and committed to finding ways to improve the lives of MDS patients and those who care for them. Momentum has been created for future MDS walks in more cities across the country!



1ST ANNUAL
CHICAGO
Awareness Walk/Run



2ND ANNUAL
BOSTON
Awareness Walk/Run

ADVANCING RESEARCH & PATIENT CARE

15TH ANNUAL INTERNATIONAL SYMPOSIUM
ON MYELODYSPLASTIC SYNDROMES
COPENHAGEN, DENMARK

The International Symposium on Myelodysplastic Syndromes is a one-of-a-kind gathering that brings together the global MDS professional community with the aim to promote an ongoing exchange of information relating to MDS. Attendees **advanced** daily practice, as well as research and patient care around the globe. **Explored** latest updates, research, and hot topics. They **connected** with international experts, partners and colleagues and established new levels of collaboration. **Shared** thoughts on our field and shaped new ideas to advance research and patient care.

Up to 170k people are estimated to live
with MDS in the U.S. with an estimated
87,000 new cases each year worldwide.





5 BIGGEST ACCOMPLISHMENTS IN 25 YEARS

1 IPSS/IPSS-R/Upcoming IPSS Molecular

The International Working Group for Prognosis in MDS (IWG-PM) consists of a group of international investigators aligned through the MDS Foundation whose focus is aimed at defining the clinical and biologic features of MDS thus providing the foundation for understanding the nature and potential for progression of this spectrum of disorders. This foundation is the International Prognostic Scoring System (IPSS), the IPSS-R (revised/updated system), and the soon to be IPSS-Molecular. The group continues to generate programs leading to seminal projects and publications characterizing and classifying the disease. Current group investigations include determining the impact of mutational features that further delineate disease status and potential therapeutic targets providing novel treatment approaches for MDS.

2 MDSF International Congress and ASH Symposia

Healthcare professional education is very important to the mission of MDSF. The MDSF International Congress is the premier forum for presenting the latest advancements in myelodysplastic syndromes and offers the ultimate platform to enhance scientific knowledge, establish new collaborations and bring together the MDS community. The Congress covers the most recent discoveries in the field, basic and translational research as well as all relevant clinical aspects of MDS diagnosis, prognosis, and management. We have held 15 Congresses since the program's inception in 1988. The 16th Congress is scheduled for Toronto in 2021. Equally important is our annual American Society of Hematology (ASH) Symposium held preceding the annual ASH meeting. To date, we have hosted 23 professional education symposia at this annual meeting.

3 Research Grant Program

The MDS Foundation, Inc.'s Young Investigator Grant program provides an investigator, aged 40 years or less, the opportunity to initiate, continue or complete a project that focuses on either basic or clinical management into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis and treatment of the Myelodysplastic Syndromes. We have provided more than \$350K in grant support to date and that number will more than double in the next two years.

4 MDS Centers of Excellence

The MDS Centers of Excellence (CoEs) form the referral base for patients contacting the Foundation for second opinions and/or referrals to a specialist in MDS. To be recognized as a Center of Excellence, an institution must have an established university (or equivalent) program; recognized morphologic expertise in MDS; available cytogenetics and/or molecular genetics; ongoing research, including Institutional Review Board-approved clinical trials; and documentation of peer-reviewed publications in the field. The MDSF CoE physicians and nurses are exceptional partners and vital to our mission.

5 Regular live patient meetings across the USA and globally

These ongoing meetings address quality-of-life issues for MDS patients and their caregivers. Based on our steady communication with patients and caregivers, we feel there is a significant need to further educate MDS patients and their caregivers regarding the most updated treatment options, clinical studies, referral opportunities to MDS Center of Excellence specialists, and additional ongoing and updated information concerning myelodysplastic syndromes (MDS), acute myeloid leukemia (AML), and other related myeloid neoplasms (MPNs). Patients in all stages of their disease are encouraged to attend. Our goal is to create a safe and comfortable space for patients and caregivers to learn from each other as well as the expert speakers from our Centers of Excellence and Nurse Leadership Board. We host at least 10 in-person meetings in the USA each year and 1-3 meetings outside the USA.



WATCH & WAIT MDS DOESN'T HOLD ME BACK.

BRIAN ANDERSON, MDS PATIENT

My story begins after a routine, annual check-up with my doctor in 2013. I was 49 years young. Overall, my exam was uneventful, but a few days after my examination I received a call from the doctor's office asking me to return for a second blood draw. The anxiety began to climb when he referred me to a hematologist/oncologist. Healthy people don't need to go there, do they?

The next few years were frustrating, as I went through a battery of tests and several different doctors. I did what I could to improve my health, and kept running, kickboxing, and biking. I was slow and never in contention to win a race, but always had just enough energy to finish. I still didn't know what was wrong with my blood, but at this point I felt relatively healthy and was in best shape of my life.

I was ultimately diagnosed with MDS in the fall of 2016 and underwent a flurry of treatments at the Moffit Cancer Center in Florida. While initial results were promising, my numbers eventually declined to pre-treatment levels or lower. Through all of this, the support of my wife, family, and friends was critically important.

I am now waiting to see what my future holds. That means semi-annual trips to Moffitt to see my doctor and bi-monthly blood draws. My doctor and his team are ready to perform an allogeneic stem cell transplant, the only known treatment to cure MDS, but due to my current excellent health and relatively young age, the risks associated with this procedure outweigh the benefits. The game now is to simply monitor my condition and live my life.

So, I participate in MDS walks in Boston and 5K March for Marrow runs in Washington D.C. I continue to work, travel, and spend quality time with family. I also started an MDS support group for MDS patients in the Washington DC area. It has been a wonderful and comforting experience to both share my story and listen to others. Otherwise, I keep a cautious eye on my labs, and keep a positive attitude.

Before I learned of the significant risks, a transplant was what I wanted. Now, I simply hope to live as long as I can with a good quality of life before a transplant becomes necessary. It's the best plan that I could have and I'm happy to have it!

THE FACES OF MDS



"Deciding to take more control of my future, I started a support group for patients with MDS in the Washington DC area. It has been a wonderful experience to both share my story and listen to those of the participants."

- BRIAN ANDERSON -



HISTORY OF MDS & THE MDS FOUNDATION

TIMELINE OF MDS HISTORY

EARLY 1970S

Creation of the Cooperative Leukemia Diagnostic (CLD) Working Group by the FAB Cooperative Leukemia Group

1982

FAB renamed these disorders Myelodysplastic Syndromes with 5 subtypes identified.

1991

2nd International Symposium on MDS in Bournemouth, UK

1988

1st International Symposium on MDS in Innsbruck, Austria

1976

CLD Working Group identified RAEB & CMML - These two disorders were subtypes of Dysmyelopoietic Syndromes

1994

MDS Foundation, Inc. established
3rd International Symposium on MDS in Chicago, IL, USA

1997

Inception of the MDS Center of Excellence Program

Development of the International Prognostic Scoring System (IPSS)

4th International Symposium on MDS in Barcelona, Spain

2003

7th International Symposium on MDS in Paris, France

2004

FDA Approval of Vidaza (azacitidine) - 1st treatment for MDS

2008

MDSF International Nurse Leadership Board (NLB) is established

International Working Group for the Prognosis in MDS (IWG-PM) is established

2012

Identification of gene mutations in MDS
IPSS-R Risk Assessment Calculator

2014

MDSF Partnership with the MDS/MPN International Working Group

2016

WHO Reclassification of MDS

2018

1st MDSF Regional Symposium in Brazil

2020

2nd MDSF Regional Symposium in Israel

2001

6th International Symposium on MDS in Stockholm, Sweden
WHO Classification of MDS

1999

5th International Symposium on MDS in Prague, Czech Republic

2007

9th International Symposium on MDS in Florence, Italy

2006

FDA Approval of Dacogen (decitabine)

2005

8th International Symposium on MDS in Nagasaki, Japan

FDA Approval of Exjade for Iron Overload

FDA Approval of Revlimid (lenalidomide)

Inception of the MDSF Young Investigator Grant Program

2009

10th International Symposium on MDS in Patras, Greece

2011

11th International Symposium on MDS in Edinburgh, UK

Implementation of a Global Patient Support Group Program

Refinement of the International Prognostic Scoring System (IPSS-R)

2013

12th International Symposium on MDS in Berlin, Germany

2015

13th International Symposium on MDS in Washington, DC, USA

FDA Approval of Jadenu - oral formulation of Exjade

2017

14th International Symposium on MDS in Valencia, Spain

MDSF Medical & Scientific Advisory Board is established - Mario Cazzola, Chair

MDSF Development Board is established - Deborah Peirce, Chair

2019

15th International Symposium on MDS in Copenhagen, Denmark

2021

16th International Congress on MDS in Toronto, Canada

HOW YOU CAN GET INVOLVED

► Become a Member

Become a Member of the MDS Foundation community. Get access to patient advocacy services and support the mission of improving the lives of patients with myelodysplastic syndromes. **Join online at mds-foundation.org.**

► Register for an Awareness Run/Walk Event

Participate in one of several awareness events. Join an existing team or start your own! These events give you an opportunity to share your story, meet people in the MDS community, and help bring awareness to this rare disease.

► Start a Support Group

Support groups provide patients, caregivers and their family members with a network of individuals experiencing similar issues. We will provide you with a toolkit and materials to start your own support group.

► Host a Fundraising Event

You can create your own fundraiser event – including golf tournaments, special dinner events, community runs or just about anything else you can dream up. If you want something that requires a little less effort, you can create your own virtual fundraiser on our Facebook page. Easy to do and is a great way to grow awareness for MDS with your social network.

► Attend a Foundation Educational Event

Learn about the most updated treatment options, clinical studies, referral opportunities to COE specialists, and updated information concerning MDS, acute myeloid leukemia (AML), and other related myeloid neoplasms (MPNs).

► Submit your story to be shared with others

You will be able to share your experience and unique insights by submitting your story, which can provide comfort to those going through something similar. You'll likely find it therapeutic for yourself too.

► Download the MDS Foundation Mobile App

Have MDS information at your fingertips! The app provides patients, caregivers, and healthcare providers with quick access to the important services that the MDS Foundation provides. These services include our worldwide Centers of Excellence, upcoming Patient Forums and Events, as well as our numerous online resources. Available in the Google Play Store and iTunes.

FOR HEALTHCARE PROFESSIONALS:

► Apply to be listed as a Center of Excellence in MDS

Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? Visit us online to find out how to qualify and apply.

► Submit your research publications in MDS to be shared with others

We are happy to share new developments and research with our audiences. Please contact the Foundation office to learn more.

Visit mds-foundation.org to discover how you can join, donate and volunteer.





THE FACES OF MDS

"My mother gave me the gift of life as her own was coming to an end. She continued to support and be generous, actually generative, to my daughters and me until the very end. Her generativity fueled a desire in me to be an advocate and supporter of MDS patients."

— DEBORAH PEIRCE —



MY JOURNEY TO BECOMING A PATIENT ADVOCATE

DEBORAH PEIRCE, DAUGHTER OF MDS PATIENT

Ten years before my mother's passing, there were signs that something was wrong. One day, she and my father were riding bikes when she fell, resulting in huge, ghastly bruises, clearly out of proportion to her injuries.

As captured in the book, *Voyage of the Suzy Wong*, my father was an avid adventurer who traveled around the world, including Barbados, where he and my mother met at the beach, she wearing a yellow swimsuit. As fate would have it, he was colorblind, and yellow was one of the few colors he could see. After marriage, my mother earned a degree from Northwestern University and taught ESL in the Chicago area, where my brother and I grew up. Later, my parents enjoyed an extended residency in China, where they taught business and English classes at Nanjing University. China was also where my mother's medical issues first surfaced; in 1997 she was diagnosed with pancytopenia with bruising. In 1999, the same year she became a grandmother, she was diagnosed with MDS.

MDS was an unknown and life-threatening rare blood disease to my family, and learning to care for her was an adjustment for us all. By 2002, despite our best efforts and robust medical intervention, her condition began to deteriorate. In 2003, she began to rapidly decline with progressive thrombocytopenia.

In 2003 I was offered an important assignment in China, but how could I leave my mother at the time she needed me the most, and take far away from her two grand-daughters who were the lights of her life? My mother told me to go to China; and I did, not knowing what would happen to her, but she fought hard and stayed alive until I returned from my assignment abroad. We had almost a full year together before she passed in 2007.

"Thank you, Mom. You have given me all that I need to stand on my own." After I whispered these words, she took her last breath.

My mother's MDS experience inspired me to become an advocate for patients with rare diseases, and today I am privileged to sit on the Development Board for the MDS Foundation where we are focused on fundraising to support the MDSF mission.

OUR SUPPORTERS

Thank you to our partners for their continued support of the MDS Foundation. Our dedicated work to aid and educate patients and professionals is made possible through these valuable partnerships!

Accelaron Pharma
Agiros Pharmaceuticals
Amgen
Astex Pharmaceuticals
Celgene Corporation
Daiichi Sankyo, Inc.
Gabrielle's Angel Foundation
Gamida Cell
Geron Corporation
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Pfizer
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Syros Pharmaceuticals, Inc.
Taiho Pharmaceutical
Takeda Pharmaceutical Company

PROUD MEMBERS:

KNOW AML



25th
Anniversary

"When I was so desperate to find a healthcare provider who was empathetic to my dad, you took time to listen and responded immediately. You will never know how much that meant."

— DAUGHTER OF MDS PATIENT

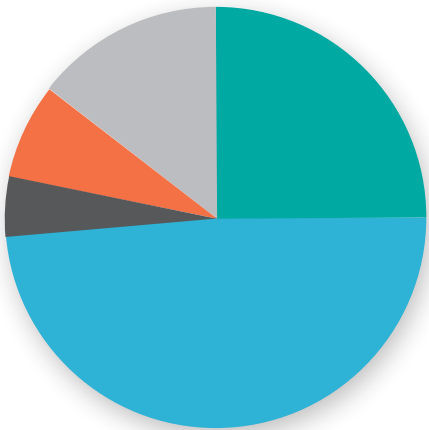


2019 FINANCIAL HIGHLIGHTS

The figures on this page show the financial activities of the MDS Foundation for the fiscal year ending on December 31, 2019

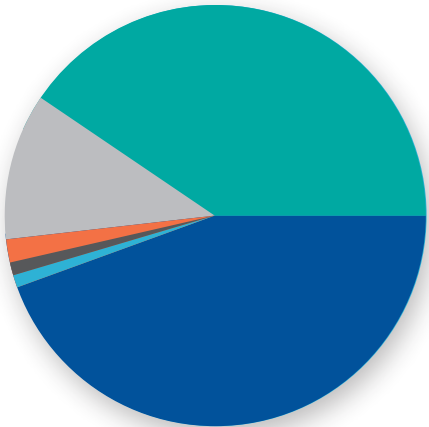
2019 EXPENSES - \$2,450,440

Professional Education & Training.....	45%
Patient Advocacy.....	25%
Research.....	18%
Fundraising.....	7%
Management.....	5%



2019 REVENUE - \$3,004,295

Special Events.....	44%
Pharmaceutical Grants.....	39%
Contributions.....	13%
Member Dues.....	2%
Program Services	1%
Other	1%



OUR TEAM

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- Janice Butchko**, Project Manager
- Lea Harrison**, Senior Project Manager
- Audrey Hassan**, Patient Liaison
- Deborah Murray**, Administrative Support



WWW.MDS-FOUNDATION.ORG

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