



2018 ANNUAL REPORT

the myelodysplastic syndromes foundation, inc.



PATIENT SUPPORT AND EDUCATION • PROFESSIONAL EDUCATION • INTERNATIONAL WORKING GROUPS • RESEARCH

TOGETHER

we are a community resource of hope
for those living with mds

FROM OUR CHAIRMAN

Dear Friends and Colleagues,

Over 24 years ago, the MDS Foundation, Inc. was established by a global group of physicians and researchers to promote the ongoing exchange of information relating to MDS. Until the Foundation was created, no formal organization had been devoted solely to MDS. Due to a persistent rise in awareness and diagnosis of MDS, as well as continued growth in the research efforts surrounding MDS, the need for our Foundation has only increased over time. Each year we continue to expand our reach worldwide to meet the many growing needs of the patients and families affected by myelodysplastic syndromes, as well as the healthcare professionals who dedicate their lives to caring for these patients and continue to evaluate novel treatment options in the search for cures for this disease.



In 2018, we continued our efforts to expand our focus to include education and research into related myeloproliferative neoplasms (MPN), the so called overlap syndromes, especially given their similarity to MDS in their clinical presentation and the mutations that accompany them. Our new MDS/MPN patient and caregiver resource, Building Blocks of Hope®: MPN Edition, was completed in 2018 to meet the needs of patients who are LIVING with MPNs.

As we move forward, we will further expand our scope to include education and research into acute myeloid leukemia (AML). We are planning the development, implementation, and health outcomes evaluation of an interactive, highly visual, evidence-based resource entitled: **You and AML: An Animated Patient's Guide to AML, AML-MRC and tAML for Shared Decision-Making and Optimal Health Outcomes**. This AML patient education resource will enable patients to better understand critical disease management interventions, be more informed, and actively participate with health providers in their own AML decisions.

New in 2018, we hosted our first Regional Symposium, the **Latin American MDS Foundation Symposium**, in Sao Paolo, Brazil during the Annual Congress of the Brazilian Association of Hematology and Cell Therapy. Well-known experts in the field covered topics that spanned from inherited predisposition to developing myeloid malignancies to age-related clonal hematopoiesis and its clinical implications. Case-based discussions helped participants understand the clinical-decision making processes regarding diagnosis, prognostication and treatment of myelodysplastic syndromes and related disorders. **The Second Regional Symposium on MDS** will be held in Tel Aviv, Israel in March 2020.

Lastly, but of vital importance, we've embarked on a series of awareness events to start a movement with helping to further spread awareness and bring attention to MDS among the physician community as well as the general public. We hosted our first **MDS Awareness Walk** in Boston. We feel the time is now to elevate the conversation around the unmet needs of those living with MDS; to bring together the MDS and rare disease community and create new connections; to reinforce our commitment, along with our partner organizations, to help improve the lives of MDS patients and those who care for them; and to establish the need and momentum for future MDS walks across the country.

In our 2018 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 aim to have new therapies and more hope for patients and families battling these diseases. Thanks to the tireless work of so many, the Foundation's efforts keep growing stronger. 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.

Stephen Nimer, MD
Chair, MDS Foundation, Inc.

www.mds-foundation.org

A small Foundation with a remarkable global outreach! We put support and education first!

3.5 M VISITORS

OVER THE PAST 3 YEARS OVER 3.5 MILLION PEOPLE VISITED THE MDSF WEBSITE

400 REFERRALS

NEARLY 400 PATIENTS REFERRED TO MDS SPECIALISTS IN 2018

1,800 PATIENTS

NEARLY 1,800 PATIENTS AND CAREGIVERS INDIVIDUALLY COUNSELED IN 2018



The MDS Foundation, Inc. is an international non-profit advocacy organization whose mission is to support and educate patients and healthcare providers with innovative research into the fields of MDS, Acute Myeloid Leukemia (AML) and related myeloid neoplasms in order to accelerate progress leading to the diagnosis, control and cure of these diseases.

Initiated the development of

35

PATIENT SUPPORT GROUPS WORLDWIDE



19

LANGUAGES

MDS FOUNDATION RESOURCES translated into nineteen languages

30,000⁺

HEALTHCARE PROFESSIONALS

Educated thru GLOBAL SYMPOSIA

over the past 20 years



2,000⁺

People have downloaded MDSF MOBILE APPLICATIONS



We have grown the MDS CENTERS OF EXCELLENCE program from 10 Centers in 1997 to

184

CENTERS OF EXCELLENCE WORLDWIDE

1,500⁺

PATIENTS & CAREGIVERS

Educated at our LIVE PATIENT FORUM events over the past 3 YEARS

600⁺

INFORMATION PACKETS distributed FREE-OF-CHARGE to newly diagnosed patients in 2018

5,000⁺

PRINTED RESOURCES distributed globally in 2018



37,000 VISITORS

viewed our new YOU AND MDS animated video series resource in its first year



MDS FOUNDATION MOBILE APP

THE MDSF APP IS A NEWLY
DEVELOPED MOBILE APP FOR
SMARTPHONES AND TABLETS!

This 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.

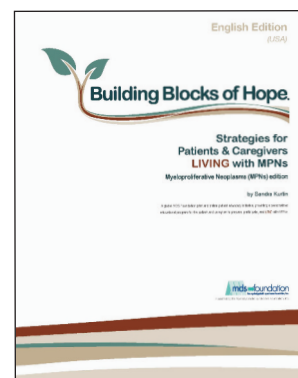
"I cannot tell you how helpful the forum was and how much we all enjoyed it. Everything was very informative, well put together and all of you are so knowledgeable, kind and genuine."

ALISSA M

PATIENT RESOURCES

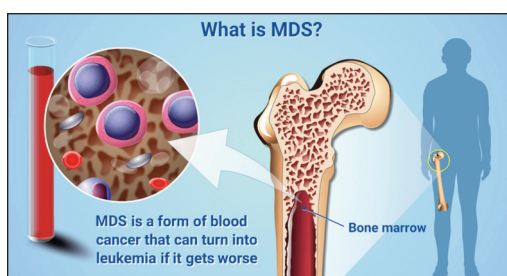
The primary focus of the Foundation is patient advocacy, support and education. We provide extensive resources to patients and their families about MDS treatment options, upcoming clinical trials, and recent research so that patients can make educated decisions about treatment and take a more active approach to their care. One such program is our **BUILDING BLOCKS OF HOPE® – STRATEGIES FOR PATIENT AND CAREGIVERS LIVING WITH MDS**, which is an extensive print and online patient initiative that provides a personalized education program. This resource is now offered in a myeloproliferative neoplasms (MPNs) edition.

We also provide various printed and electronic patient resources and handbooks that are available in multiple languages. In addition to the education component, the MDS Foundation develops patient support groups, hosts live Patient and Family Forums, offers a patient message board through the MDSF website, and provides access to a full-time Patient Liaison who is available to advise and refer patients to the appropriate resources, studies, and/or specialists.



EVERY DAY APPROXIMATELY 238 PEOPLE
WORLDWIDE ARE DIAGNOSED WITH MDS.

We are excited to announce the MDS Foundation's new online patient education resource, titled **"YOU AND MDS: AN ANIMATED PATIENT'S GUIDE TO MYELODYSPLASTIC SYNDROMES"**. This resource is intended for patients with MDS, as well as family members and caregivers. You will find expert advice about MDS to help you discuss key issues with your health care provider and make important decisions related to management and treatment. Easy-to-understand animations with audio narration, expert video explanations, patient interviews, illustrated slide shows, and educational downloads are available to you. You are invited to provide



feedback to help direct future content as this site becomes part of your personal information resource on MDS. We welcome you to this online community resource to improve your quality of life and health outcomes.

In response to the needs expressed by patients, families, and healthcare professionals, we have established patient support programs, professional education initiatives, and funded research efforts

MDS CENTERS OF EXCELLENCE

As part of our patient referral system, we currently recognize **184** MDS Centers of Excellence worldwide. These treatment centers undergo careful review and must meet the following criteria:

- 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
- Documentation of peer-reviewed publications in the field

PROFESSIONAL EDUCATION

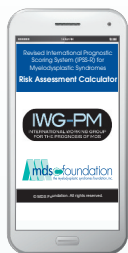
In an effort to advance medical research and improve the quality of healthcare for MDS patients, we disseminate information to professionals about new treatment options and facilitate an informational exchange between healthcare providers.



We host an **MDS BREAKFAST SYMPOSIUM AT THE ANNUAL AMERICAN SOCIETY OF HEMATOLOGY (ASH)** which allows us to directly educate more than **500 hematologists**, with additional access to over 20,000 hematologists throughout the full congress meeting.

We host a biennial **INTERNATIONAL CONGRESS** and **REGIONAL SYMPOSIA**, with the first regional symposium held in Sao Paulo, Brazil in 2018 during the Annual Congress of the Brazilian Association of Hematology and Cell Therapy. Well-known experts in the field covered topics that spanned from inherited predisposition to developing myeloid malignancies to age-related clonal hematopoiesis and its clinical implications. Case-based discussions helped participants understand the clinical-decision making processes regarding diagnosis, prognostication and treatment of myelodysplastic syndromes and related disorders.

In addition to these programs, the MDS Foundation also maintains an **ONLINE CLINICAL TOOLBOX** resource for healthcare providers. This clinical toolbox includes a Learning Management System where professionals can earn **CONTINUING MEDICAL EDUCATION CREDITS** as well as highlights of the latest literature in MDS.



IPSS-R CALCULATORS

OUR ONLINE BASIC CALCULATOR

The Basic calculator tool includes clinical features of marrow blasts, cytogenetics, depth of cytopenias and age.

OUR ONLINE ADVANCED CALCULATOR

The Advanced calculator tool includes the above features plus the additive differentiate features for patient survival of performance status, serum ferritin, LDH, beta-2 micro globulin and marrow fibrosis.

**60-170K
PEOPLE**

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

INTERNATIONAL WORKING GROUPS AND GENERAL RESEARCH

The Foundation oversees three working groups dedicated to specific MDS-related topics:

INTERNATIONAL WORKING GROUPS



INTERNATIONAL WORKING GROUP FOR PROGNOSIS IN MDS (IWG-PM)

The objective of this group is to continue to refine the currently accepted and utilized prognostic scoring systems based on the current research discoveries. (Responsible for continued revisions to the International Prognostic Scoring System (IPSS) for MDS.)



MDS/MPN INTERNATIONAL WORKING GROUP (MDS/MPN IWG)

The overarching goal of this group is to identify key knowledge gaps in the area of MDS/MPNs (Myeloproliferative Neoplasms) and facilitate international, collaborative, translational science geared to rapidly improve our understanding of these neoplasms. (Developed to foster collaboration among translational scientists in the area of myeloid malignancy to better define, risk stratify, and treat patients with overlap syndrome.)



INTERNATIONAL NURSE LEADERSHIP BOARD (NLB)

Composed of more than 30 members worldwide, and includes 3 subcommittees: *Professional Education, Patient Education, and Quality of Life.*

RESEARCH GRANTS

From 2012–2018, **WE HAVE AWARDED MORE THAN \$300,000 IN GRANTS THROUGH OUR YOUNG INVESTIGATOR GRANT PROGRAM.** These funds have helped to make great strides in research into areas such as aberrant mRNA splicing induced by ZRSR2 mutation in the pathogenesis of myelodysplastic syndromes, unraveling the role of alternative splicing in normal and MDS hematopoietic stem and progenitor cells, HIF-1α as a central pathobiologic mediator of myelodysplastic syndromes, and targeting TP53 gene mutations in myelodysplastic syndromes through functional reconstitution and immune activation. Providing the resources for these research projects directly improves the quality of life of MDS patients and their caregivers.

The Foundation also assists our industry partners through the clinical trial process by raising awareness of these vital trials, and incorporating the patient voice into these trials in an effort to increase enrollment of MDS patients. These research related efforts each year bring us closer to a cure for MDS.

Helping to further
spread awareness
and bring attention
to this disease among
the physician
community
as well as the
general public

MDS AWARENESS

MDS AWARENESS WALK – BOSTON 2018 – THE TIME IS NOW.

Although great strides have been made, more work needs to be done in MDS and to better understand the needs of patients. Inspired by those impacted by MDS, our hope with this first **MDS FOUNDATION MDS AWARENESS WALK** is to start a movement with helping to further spread awareness and bring attention to this disease among the physician community as well as the general public.

Our goals for these events are to:

- Elevate the conversation around the unmet needs of those living with MDS.
- Bring together the MDS and rare disease community and create new connections.
- Reinforce our commitment, along with our partner organizations, to help improve the lives of MDS patients and those who care for them.
- Establish the need and momentum for future MDS walks across the country.



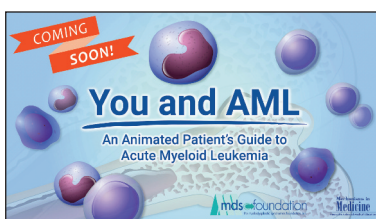
1 OUT OF 3 MDS PATIENTS

(or 30%) progress
to acute myeloid
leukemia (AML).

MOVING FORWARD

In addition to our current patient and professional programming, the Foundation will be moving forward in some new and exciting ways...

- **ADDITIONAL MPN RESOURCES.** The development of an MPN mHealth application — *MPN Direct* that includes tools to improve health and illness self-management, health literacy, technology literacy, health communication, shared decision-making and empowerment.
- **YOU AND AML — An Animated Patient's Guide to Acute Myeloid Leukemia, AML-MRC and tAML for Shared Decision-Making and Optimal Health Outcomes.** Easy-to-understand animations with audio narration, expert video explanations, patient interviews, illustrated slide shows, and educational downloads.



Viewers are invited to provide feedback to help direct future content. We are excited about this new online community resource to improve quality of life and health outcomes.

- **MDS AWARENESS WALKS.** Boston and Chicago 2019 — continuing our efforts to spread awareness of MDS — bringing together the MDS and rare disease community and creating new connections.



- The continuation of our **BIENNIAL INTERNATIONAL CONGRESS MEETINGS** devoted to healthcare professionals — the 15th International Congress on Myelodysplastic Syndromes in Copenhagen, Denmark, May 8–11, 2019 and the 16th International Congress on Myelodysplastic Syndromes in Toronto, Canada, May 5–8, 2021.



- The continuation of our Regional Symposia series for healthcare professionals **2ND REGIONAL SYMPOSIUM ON MYELODYSPLASTIC SYNDROMES, MARCH 5-6, 2020 IN TEL AVIV, ISRAEL**

HOW YOU CAN HELP

JOIN THE FOUNDATION AS A MEMBER*

- You are part of the solution to change MDS outcomes. Your membership fee helps support global physician and patient educational initiatives, and helps to empower patients with courage and hope.
- Updates on the status of our Global Centers of Excellence and their live patient and family forum events that allow for more rapid dissemination of new research and treatment developments.
- Information on the latest clinical trials to potentially share or participate in.
- Access to MDS awareness materials to share with family and friends.
- Opportunities to participate in or host support group events with your friends and community.
- Receive two printed issues of *The MDS News*, which includes the latest on MDS research as well as inspiring patient and caregiver stories.

DONATE TO SUPPORT OUR MISSION*

- All donations are tax-deductible. Thank you in advance for your support!

AMAZON SMILE

- When you shop with Amazon Smile, Amazon will donate 0.5% of the price of an eligible purchase to the MDS Foundation. All you have to do is select Myelodysplastic Syndromes Foundation as your charity of choice.



VOLUNTEER*

- Volunteers are vital to our mission.

***PLEASE VISIT**
<https://www.mds-foundation.org>
to discover how you can join,
donate and volunteer



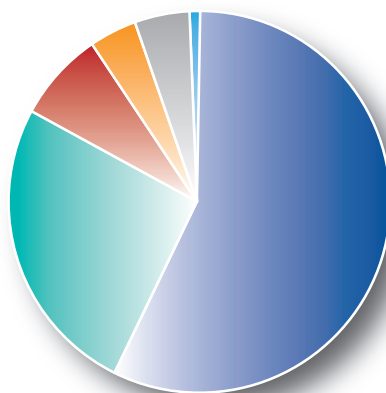
12-20K MDS PATIENTS

new cases of MDS are reported every year in the US, with an average of 33-55 people diagnosed in the US every day.

"Thank you for all your help when I was first diagnosed 2 years ago. Your kindness, understanding and knowledge were what helped me get through a very difficult time."
BARBARA E.

FINANCIALS

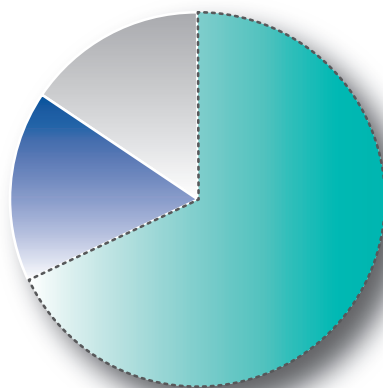
2018 REVENUE



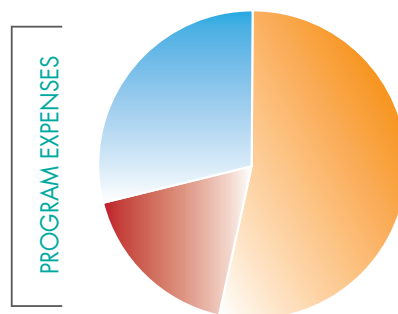
- Pharmaceutical Grants (57%)
- Contributions (26%)
- Special Events (7%)
- Program Service Revenue (4%)
- Membership Dues (5%)
- Other Revenue (1%)

2018 marks the debut of our very first national walk-a-thon fundraising event held in Boston, MA. Increased fundraising expenditures arising from this event, combined with new accounting rules contributed to a temporary decrease in program expenditures and an increase in fundraising expenditures. The proceeds raised in 2018 were reinvested in programming needs for 2019.

2018 EXPENSES



- Program (68%)
- Management (17%)
- Fundraising (15%)



- Patient Support (53%)
- Professional Education (18%)
- Research (29%)

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!

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Deborah Murray, Administrative Support

WHAT IS MDS?

The myelodysplastic syndromes (MDS) are a group of bone marrow failure disorders. The bone marrow is the factory for the production of blood cells including red blood cells (energy), white blood cells (immune system), and platelets (clotting).

In MDS, the bone marrow is damaged and fails to produce enough blood cells (cytopenias).

MDS is considered a rare disease, with relatively low incidence rates worldwide. However, the incidence may be increasing as the population ages and more individuals are exposed to toxic chemicals and/or prior chemotherapy treatments.



The MDS Foundation, Inc., 4573 South Broad St., Suite 150, Yardville, NJ 08620

www.mds-foundation.org

The MDS Foundation is a publicly supported organization, exempt from federal income tax under section 501(C)(3) of the IRS code.