

# Dr. Joe, Diversity, Disparity and Myeloma

***PMMNG***

***January 2021***

**Joseph Mikhael, MD, MEd, FRCPC**  
Chief Medical Officer, International Myeloma Foundation  
Professor, Translational Genomics Research Institute (TGen)  
City of Hope Cancer Center

# Plan for Today

- Dr. Joe's brief story
- An introduction to Disparities in Cancer and Myeloma
- Clinical Trials and The African American Community
- The IMF African American Initiative

# My Story – Personal and Professional

- My parents
- My schooling
- My experience in Canada
- My time at Mayo Clinic
- My journey to the IMF
- My passion for the underserved and vulnerable...

# What is Equity, Diversity and Inclusion?

- **Equity** means to guarantee of fair treatment, access, opportunity, and advancement for all while striving to identify and eliminate barriers that have prevented the full participation of some groups.
- **Valuing diversity** means that we recognize and respect everyone's unique qualities and attributes.
- **Inclusion** means that all individuals feel respected, accepted and valued.

# **Important Facts about Myeloma and African Americans**

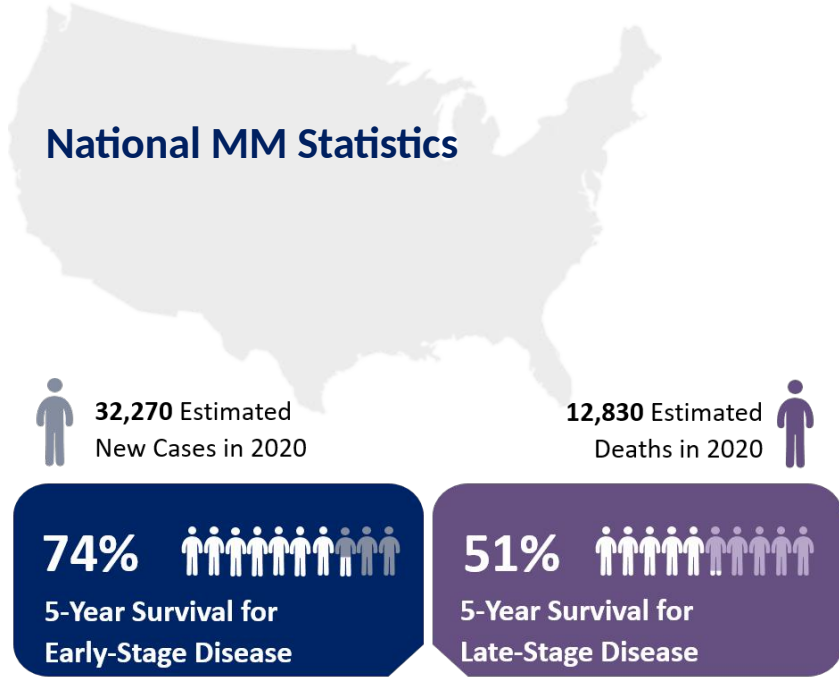
1. Myeloma is the most common hematologic cancer in African Americans
2. MGUS and Myeloma is TWICE as common in African Americans
3. Survival improvements in myeloma have not been as pronounced in African Americans (For every 1.3 years of life gained for Whites, only 0.8 years of life gained for African Americans)
4. African Americans are younger at diagnosis by about 5 years
5. There is a longer time to diagnosis from the onset of symptoms

# **Important Facts about Myeloma and African Americans**

6. African Americans are less likely to receive TRIPLET therapies
7. African Americans are less likely to receive Stem Cell Transplants
8. Although African Americans comprise 20% of all MM patients, they only represent 5-6% of patients on clinical trials
9. There are biologic differences in African Americans with MM that may lead to lower risk disease
10. When African Americans receive equal access care, their survival outcomes are equal, and at times, better than Whites

# Multiple Myeloma Snapshot

## National MM Statistics



## Trends in MM Natural History by Race

<b>Genetics</b>	<ul style="list-style-type: none"> <li>➤ IgH translocations <b>more common</b> in AA patients: t(11;14), t(14;16), t(14;20)</li> <li>➤ TP53/17p deletions <b>less common</b> in AA patients</li> </ul>
<b>MGUS</b>	<ul style="list-style-type: none"> <li>➤ 3-fold <b>more common</b> in AA patients</li> <li>➤ <b>Earlier age of onset</b> in AA patients</li> </ul>
<b>MM Incidence</b>	<ul style="list-style-type: none"> <li>➤ <b>Higher incidence</b> in AA vs White patients:               <ul style="list-style-type: none"> <li>• 15.9 vs 7.5 cases per 100,000 per year</li> </ul> </li> </ul>
<b>MM Mortality</b>	<ul style="list-style-type: none"> <li>➤ <b>Survival advantage</b> in AA vs White patients:               <ul style="list-style-type: none"> <li>• SEER analysis (2019), 5-year OS:                   <ul style="list-style-type: none"> <li>• 53.9% vs 51.3%</li> </ul> </li> <li>• VA analysis (2000-2017), median OS:                   <ul style="list-style-type: none"> <li>• 5.07 vs 4.52 years (<math>P &lt; .001</math>)</li> </ul> </li> </ul> </li> </ul>

AA = African American; MGUS = Monoclonal Gammopathy of Undetermined Significance; OS = Overall Survival

American Cancer Society. Multiple Myeloma. [www.cancer.org/](http://www.cancer.org/). Accessed 07/10/2020; Baughn LB, et al. *Blood Cancer J.* 2018;8(10):96; DeSantis CE, et al. *CA Cancer J Clin.* 2019;69(3):211-233; Marinac CR, et al. *Blood Cancer J.* 2020;10(2):19; Fillmore NR, et al. *Blood.* 2019.133(24):2615-2618.

# Disparities in Access to Novel Therapy for MM

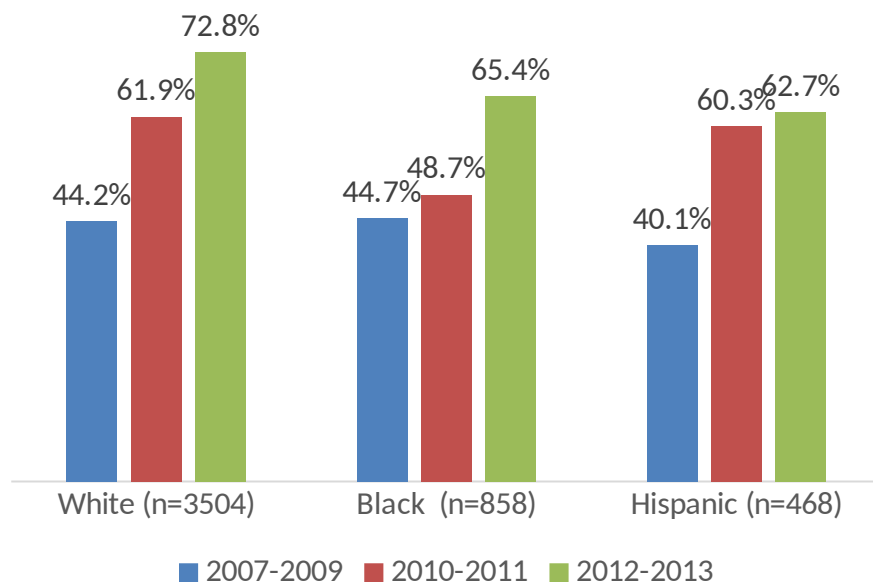
Patients with an MM Diagnosis in the SEER Medicare (2007-2013) Database

	White (n = 3504)	Black (n = 858)	Hispanic (n = 468)
Mean age at MM diagnosis	75.8 years	71.8 years	72.7 years
Mean CCI	2.2	3.2	2.7
Median time to novel therapy*	2.7 months	5.2 months	4.6 months
P value (vs white)	--	< .001	< .05
Median time to ASCT	Not reached	Not reached	Not reached
P value (vs white)	--	.08	< .05

\*Novel therapy = lenalidomide, pomalidomide, bortezomib, or carfilzomib

ASCT = Autologous Stem Cell Transplant; CCI = Charleston Comorbidity Index  
Ailawadhi S, et al. *Blood Adv.* 2019;3(20):2986-2994.

Patients on Novel Therapy\* within 6 Months of MM Diagnosis





# Setting the Stage: ASCO 2020 Policy Statement on Cancer Disparities and Health Equity

## Areas of Focus (No. of Recommendations):

### Ensure Equitable Access to High-Quality Care (5)

- Support and promote policies, systems, environments, and practices to **address persistent barriers** to equitable receipt of high-quality cancer care across the care continuum.

### Address Structural Barriers (7)

- Encourage organizations and institutions to **internally examine** and appropriately address institutional discrimination.
- Support and equip providers to address disparate health outcomes resulting from institutional discrimination through providing **education and activities that can inform practice** and research.

“To do right by the patients we serve, we must confront and address the complex forces and systems that have created disparities in disease prevention, treatment, and research participation.”

—Lori J. Pierce, MD  
ASCO President | August 12, 2020

### Ensure Equitable Access to Research (6)

- **Understand and address ongoing barriers** and promote facilitators to equitable research participation.

### Increase Awareness and Action (3)

- Develop and disseminate appropriate **literacy materials** for providers, patients, and caregivers as well as advocacy groups.

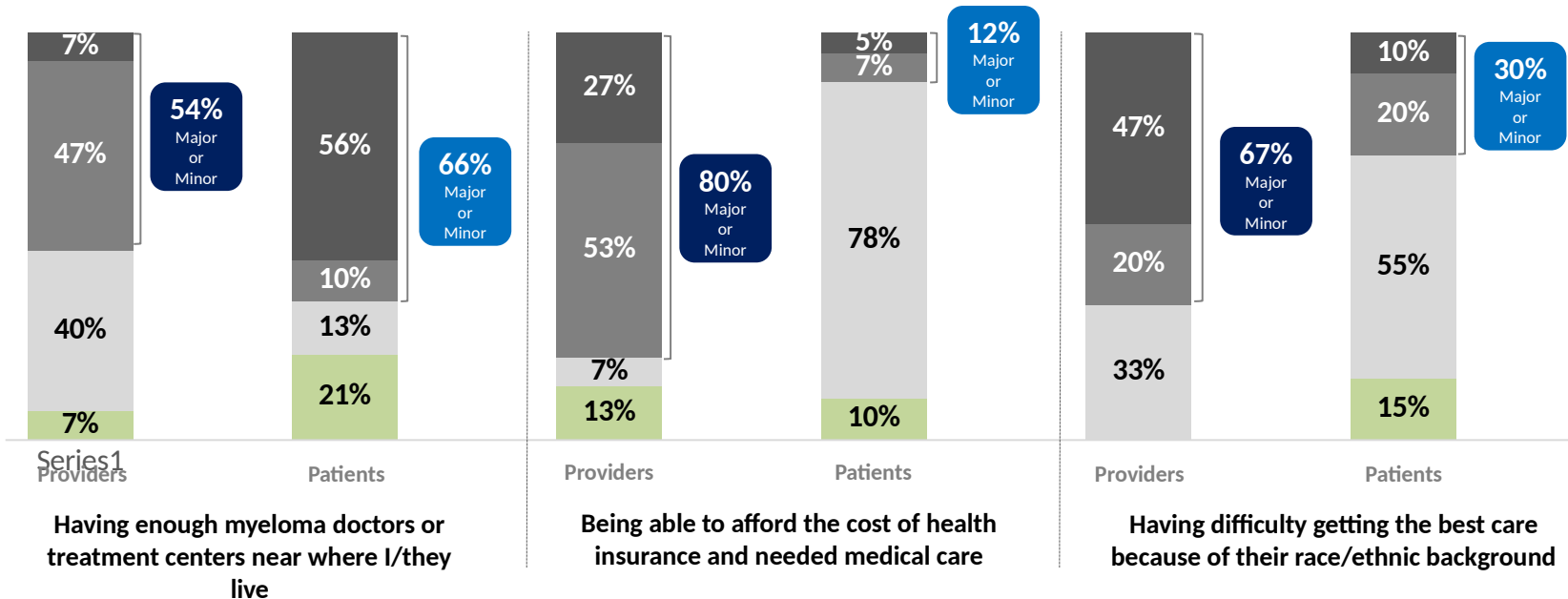


# PRIME® Data Findings: Barriers to Care Access

**Providers** | Please rate the degree of each problem (if present) for African American patients relative to other patients.

**Patients** | Thinking about other people like yourself, how much of a problem are these issues?

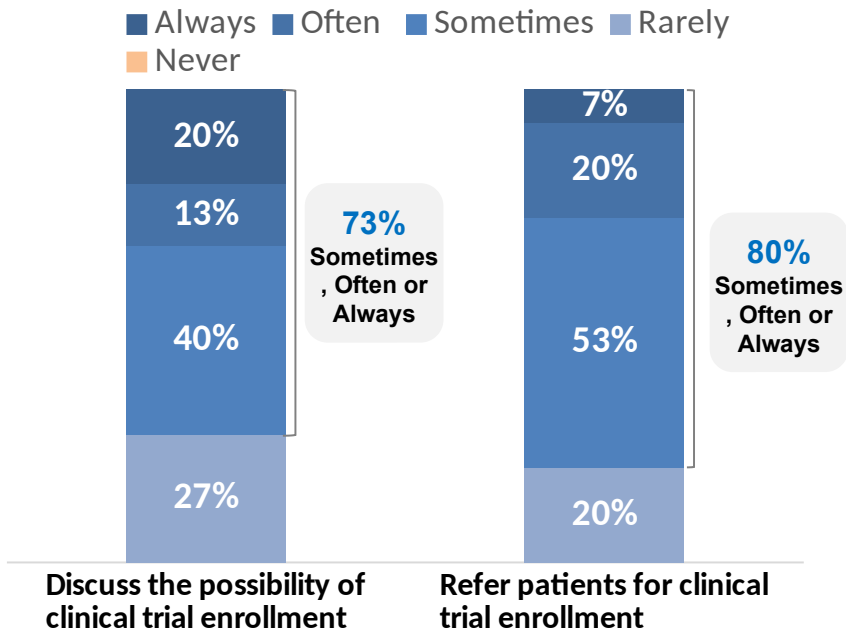
■ Major problem   ■ Minor problem   ■ Don't know





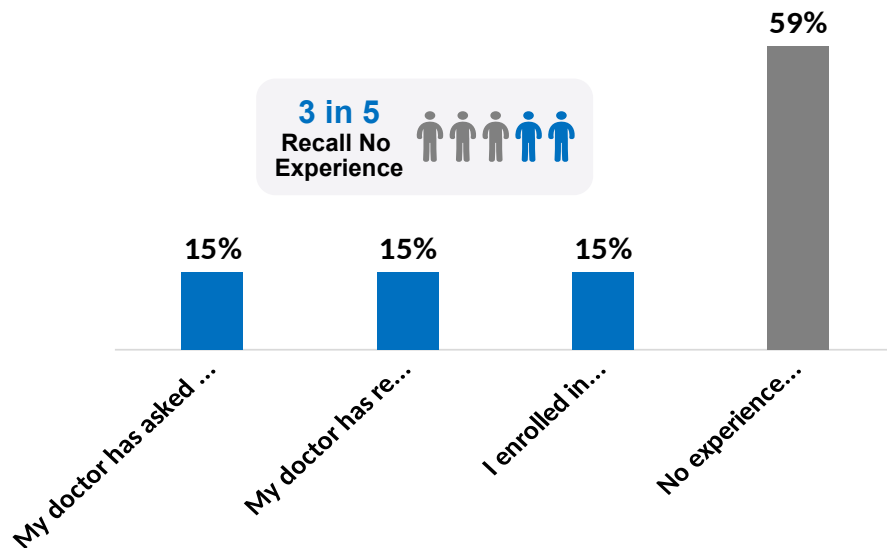
# PRIME® Data Findings: Clinical Trial Enrollment

**Providers** | Please rate how often you and your team:



N = 16 Providers

**Patients** | Please describe your experience with clinical trials for MM:

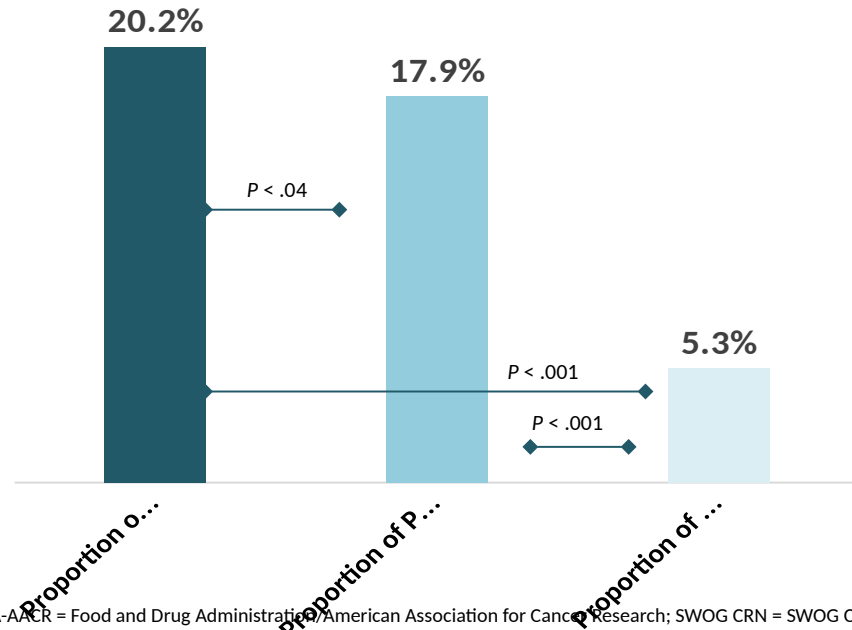


N = 39 Patients

# National Challenges in MM Clinical Trial Enrollment

## Under-Representation of Black Patients in MM Trials

Proportion of Black patients within the US MM population and in trials supporting new FDA approvals, 2008-2018:



## FDA-AACR Workshop Recommendations

FDA-AACR Workshop to Address Under-Representation of African Americans in MM Clinical Trials (February 2020):

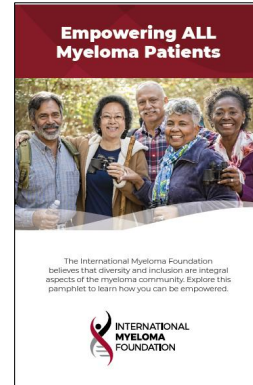
### Example working group recommendations

- Develop principles for promoting diversity
- Include diversity officer to guide design and recruitment:
  - Set concrete targets for trial enrollment
  - Define recruitment strategies to ensure study population represents disease incidence
  - Pre-specify subgroup analyses for safety and efficacy
- Educate investigators and referring physicians on cultural competence and importance of community engagement

Mikhael et al – Submitted JCO OP 2021

# IMF Mission

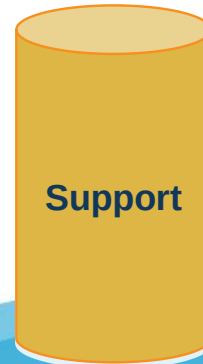
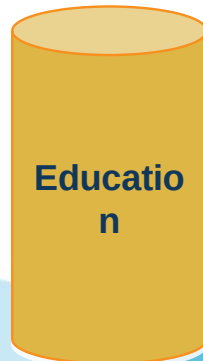
For 30 years, the mission of the IMF has been to improve the quality of life of myeloma patients while working toward prevention and a cure for all myeloma patients



**Join a Support Group**



The IMF have facilitated a network of 150 myeloma-specific support groups that hold regular meetings in the U.S. So no matter where you are, we can help you find or create a multiple myeloma support group and connect with other survivors and caregivers.



# IMF Efforts to Support All Patients



Resources in 19 languages



IMF Website



Veterans Against Myeloma  
Advocacy for Blue Water Navy Vietnam Veterans Act



Beyond Medicine's  
Barriers  
- Working toward  
access for all  
patients

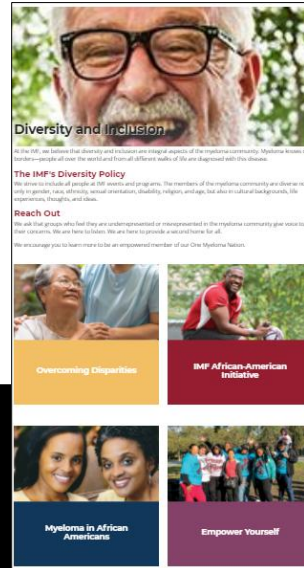


# **IMF PATIENT EMPOWERMENT MISSION**

Advancing early and equitable access to myeloma information, screening and treatment in vulnerable communities worldwide

# The African American Initiative

## *Building on the IMF's Diversity Program*





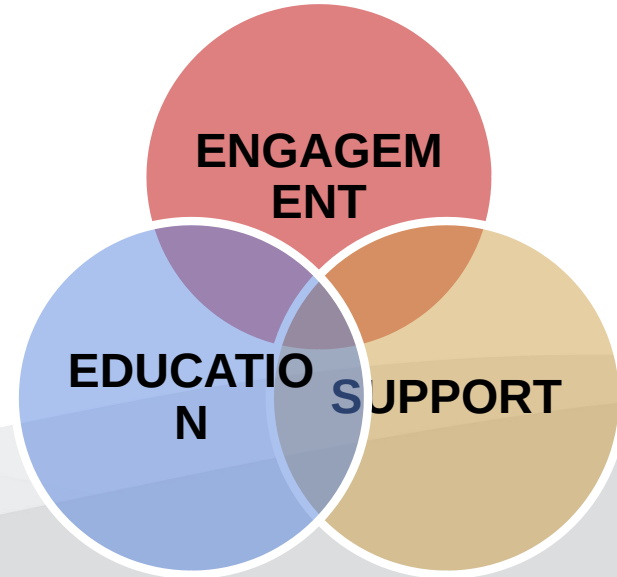
# African American Initiative

The IMF African American Initiative is one important portion of the IMF's commitment to diversity and the wellbeing of all myeloma patients worldwide.

Many groups have sought to reach out to the African American myeloma community

**HOWEVER**

The IMF is ideally poised to make a difference due to its unique mission and presence in the community



# The IMF African American Initiative

---

The **core vision** of the IMF African American Initiative is to *improve the short and long-term outcomes* of African American patients through **engagement** of the community, **education** of health care providers, and **support** of patients

The **overall objective** of the IMF African American initiative is to improve outcomes in African American patient care by:

actively **engaging** the African American community in a better understanding of myeloma,

**educating** the primary health care community regarding early and accurate diagnosis of myeloma and

**supporting** the Hematology Oncology community in their care of African American patients with myeloma

# IMF African American Initiative



# Highlights – IMF Website

3<sup>rd</sup> Quarter 2019

4<sup>th</sup> Quarter 2019

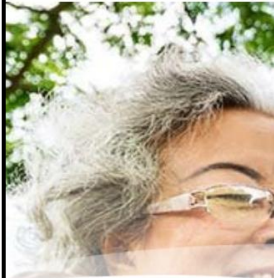
1<sup>st</sup> Quarter 2020

2<sup>nd</sup> Quarter 2020

3<sup>rd</sup> Quarter 2020

4<sup>th</sup> Quarter 2020

• IMF Diversity Website launched



## Diversity and inclusion

What are some disparities in the treatment and care of myeloma patients?

What is the IMF's African American Initiative?

How is myeloma different in African Americans?

How can the IMF help you to get the best care possible?

## How is myeloma different in African Americans?

### Myeloma Is Different in African Americans

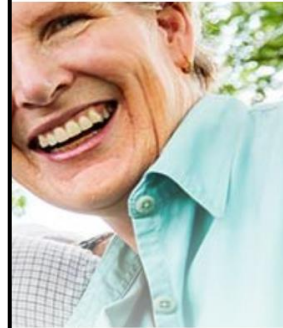
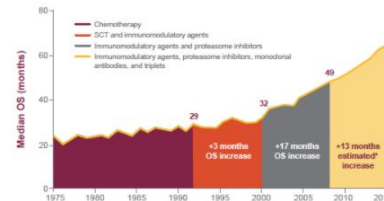
Like many patients who are diagnosed with the disease, you may have never heard of multiple myeloma. Here are some key facts about how myeloma affects African Americans:

- African Americans have an average earlier age of onset of myeloma<sup>1</sup>.
- The pre-myeloma condition, monoclonal gammopathy of undetermined significance (**MGUS**), is **more common in African Americans**. Studies in Africa have also shown this increased incidence<sup>2</sup>.
- **MGUS is twice as common in African Americans** than white Americans<sup>3</sup>

The IMF is educating the multiple myeloma community to ensure that **African Americans can be diagnosed earlier**. Earlier diagnoses are linked to better outcomes.

### Wait: Now What's That Good News Again?

Some evidence suggests the biology of myeloma may be different in African Americans when compared to white Americans.<sup>4</sup> Genetic studies are ongoing to better understand how myeloma may be different in African Americans. We do know, for example, that when African-American patients are in clinical trials, they fare as well as white patients.<sup>5</sup>



**InfoLine**  
We're here to help. Give us a call.  
U.S. & Canada: 800-452-CURE (2873)  
Worldwide: 1-818-487-7455



# Highlights – Patient & Family Seminars

3<sup>rd</sup> Quarter 2019

4<sup>th</sup> Quarter 2019

1<sup>st</sup> Quarter 2020

2<sup>nd</sup> Quarter 2020

3<sup>rd</sup> Quarter 2020

4<sup>th</sup> Quarter 2020

Saturday  
**October 3**  
2020

**NEW TREATMENTS, DIVERSITY AND CAREGIVER SUPPORT**  
Patient and Family Webinar  
7:00 AM PT/8:00 AM MT/9:00 AM CT/10:00 AM ET

INTERNATIONAL  
**MYELOMA**  
FOUNDATION



Joseph Miklosi, MD      Deepu Madduri, MD      Craig Emmitt Cole, MD      Beth Falman, PhD, MSN, APRN, BC, AOCN, FAAN

2

Build Trust

Engage the Community



Multiethnic Study Team

Cultural Competence

- PFS with disparities focus

# Highlights – Support Group Leaders

3<sup>rd</sup> Quarter 2019

4<sup>th</sup> Quarter 2019

1<sup>st</sup> Quarter 2020

2<sup>nd</sup> Quarter 2020

3<sup>rd</sup> Quarter 2020

4<sup>th</sup> Quarter 2020

21<sup>ST</sup> ANNUAL  
**SUPPORT GROUP  
LEADERS SUMMIT 2020**  
VIRTUAL PROGRAM | NOVEMBER 6-8



CELEBRATING 30 YEARS

## IMF Diversity Initiative



**Dr. Joseph Mikhael**  
IMF Chief Medical Director



CELEBRATING 30 YEARS 21st Annual Support Group Leaders Summit 2020

30

## IMF Patient Diversity Discussion



**Yelak Biru**  
Support Group Leader  
Bentonville AR



**Nancy Bruno**  
Support Group Leader  
Atlanta GA



**Thomas Goode**  
Support Group Leader  
Durham NC



**Gail McCray**  
Support Group Leader  
Southside Atlanta GA



**Tiffany Williams**  
Support Group Leader  
Orangeburg SC



CELEBRATING 30 YEARS 21st Annual Support Group Leaders Summit 2020

40

- SGL Summit Presentation on diversity

- SGL Summit disparities presentation and panel discussion

# Highlights - Publication

3<sup>rd</sup> Quarter 2019

4<sup>th</sup> Quarter 2019

1<sup>st</sup> Quarter 2020

2<sup>nd</sup> Quarter 2020

3<sup>rd</sup> Quarter 2020

4<sup>th</sup> Quarter 2020



Amy Pierre, RN, MSN, ANP-BC  
Nurse Leadership Board - IMF



Tiffany H Williams, DNP, APRN, CPNP-PC

## African American Patients With Multiple Myeloma

Optimizing care to decrease racial disparities

Amy Pierre, RN, MSN, ANP-BC, and Tiffany H. Williams, DNP, APRN, CPNP-PC

**FIGURE 1.**  
CARE OF AFRICAN AMERICAN PATIENTS WITH MULTIPLE MYELOMA: NURSING BEST PRACTICES

**ACCESS TO CENTERS OF EXCELLENCE**

- Support education on need for patients and multiple myeloma to decrease health disparities, by encouraging with a high school of patients with multiple myeloma, or at cancer centers of excellence, African American patients to access the resources available to them in order to improve outcomes
- Encourage patients with multiple myeloma to seek care at centers of excellence through foundations or groups

**TRANSPLANTATION**

- Encourage patients to understand the importance of transplant in order to improve outcomes
- Encourage patients to understand the importance of transplant in order to improve outcomes

**ADHERENCE TO THERAPY/SUPPORTIVE CARE**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment
- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**COMPLEXITY IN NURSING**

**CHARACTERISTICS OF DISEASE**

**PRESENTATION/MANIFESTATION**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**FIGURE 1.**  
CARE OF AFRICAN AMERICAN PATIENTS WITH MULTIPLE MYELOMA: NURSING BEST PRACTICES

**ACCESS TO CENTERS OF EXCELLENCE**

- Support education on need for patients and multiple myeloma to decrease health disparities, by encouraging with a high school of patients with multiple myeloma, or at cancer centers of excellence, African American patients to access the resources available to them in order to improve outcomes
- Encourage patients with multiple myeloma to seek care at centers of excellence through foundations or groups

**TRANSPLANTATION**

- Encourage patients to understand the importance of transplant in order to improve outcomes
- Encourage patients to understand the importance of transplant in order to improve outcomes

**ADHERENCE TO THERAPY/SUPPORTIVE CARE**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment
- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**COMPLEXITY IN NURSING**

**CHARACTERISTICS OF DISEASE**

**PRESENTATION/MANIFESTATION**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**FIGURE 1.**  
CARE OF AFRICAN AMERICAN PATIENTS WITH MULTIPLE MYELOMA: NURSING BEST PRACTICES

**ACCESS TO CENTERS OF EXCELLENCE**

- Support education on need for patients and multiple myeloma to decrease health disparities, by encouraging with a high school of patients with multiple myeloma, or at cancer centers of excellence, African American patients to access the resources available to them in order to improve outcomes
- Encourage patients with multiple myeloma to seek care at centers of excellence through foundations or groups

**TRANSPLANTATION**

- Encourage patients to understand the importance of transplant in order to improve outcomes
- Encourage patients to understand the importance of transplant in order to improve outcomes

**ADHERENCE TO THERAPY/SUPPORTIVE CARE**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment
- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**COMPLEXITY IN NURSING**

**CHARACTERISTICS OF DISEASE**

**PRESENTATION/MANIFESTATION**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**FIGURE 1.**  
CARE OF AFRICAN AMERICAN PATIENTS WITH MULTIPLE MYELOMA: NURSING BEST PRACTICES

**ACCESS TO CENTERS OF EXCELLENCE**

- Support education on need for patients and multiple myeloma to decrease health disparities, by encouraging with a high school of patients with multiple myeloma, or at cancer centers of excellence, African American patients to access the resources available to them in order to improve outcomes
- Encourage patients with multiple myeloma to seek care at centers of excellence through foundations or groups

**TRANSPLANTATION**

- Encourage patients to understand the importance of transplant in order to improve outcomes
- Encourage patients to understand the importance of transplant in order to improve outcomes

**ADHERENCE TO THERAPY/SUPPORTIVE CARE**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment
- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

**COMPLEXITY IN NURSING**

**CHARACTERISTICS OF DISEASE**

**PRESENTATION/MANIFESTATION**

- Encourage patients with multiple myeloma to understand the importance of adherence and adherence to the treatment

•IMF NLB  
Pub in  
CJON:  
“African  
American  
Patients  
with MM”

# More Importantly: Building Trust

---

- Open and informative dialogue about the challenges and potential solutions
- Strategic connections and partnerships in the community
- Collaboration with community organizations
- Increased IMF profile in the community



# The IMF African American Initiative

## Overarching Resources

website, InfoLine, SGs

Collaboration with existing IMF Activities  
RCWs, PFS, Publications

2019 African American Advisory Council



Thank you  
for all of  
the input  
from the  
SGLs!

## Specific Projects

1. Collaboration with  
Atrium Health (Charlotte)



- A. Community Outreach
- B. HCP Education
- C. MGUS Study

2. Other Cities  
(Atlanta, Baltimore,  
Detroit....)



- A. Community Outreach
- B. HCP Education

# THE BMS GRANT

---

Three Major interconnected projects:

**1. Engagement of the African American Community**

Raise awareness about myeloma in medical and non-medical community  
Build up campaign to peak in March during Myeloma Action Month

**2. Education of the Primary Care Community**

Focus on early and accurate diagnosis of myeloma

**3. MGUS Screening Study**

Measure true incidence in 20,000 African American patients

*All three projects will be conducted in partnership with Atrium Health (which has a huge primary care network) and Levine Cancer Institute*

# The Nursing Approach – IMF NLB

Build Trust

Engage the Community

Multiethnic Team

Cultural Competence



# Survey Results

---

*A survey conducted among 2,000 Multiple Myeloma patients, approximately 10% of whom are African American, informed next steps in this important initiative*

## Trends:



1. African Americans were more likely to have a **long delay** in diagnosis

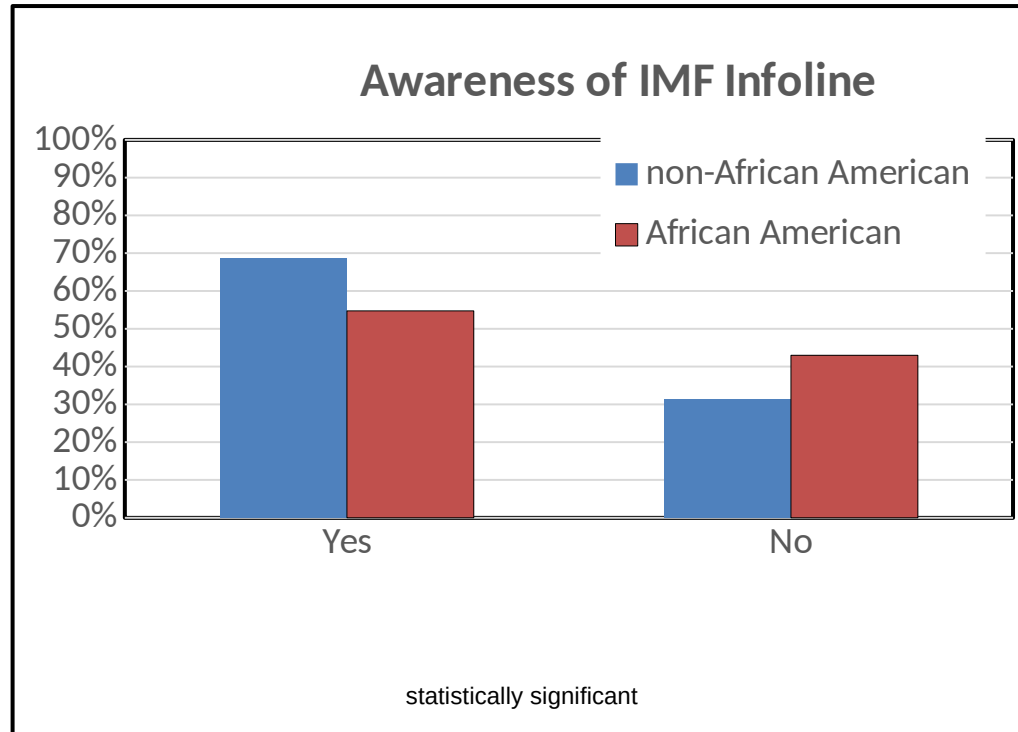


2. African Americans were less likely to have their physician order a **bone marrow** to diagnose the disease



3. African Americans were less likely to be treated with a **triplet regimen**

# Resources

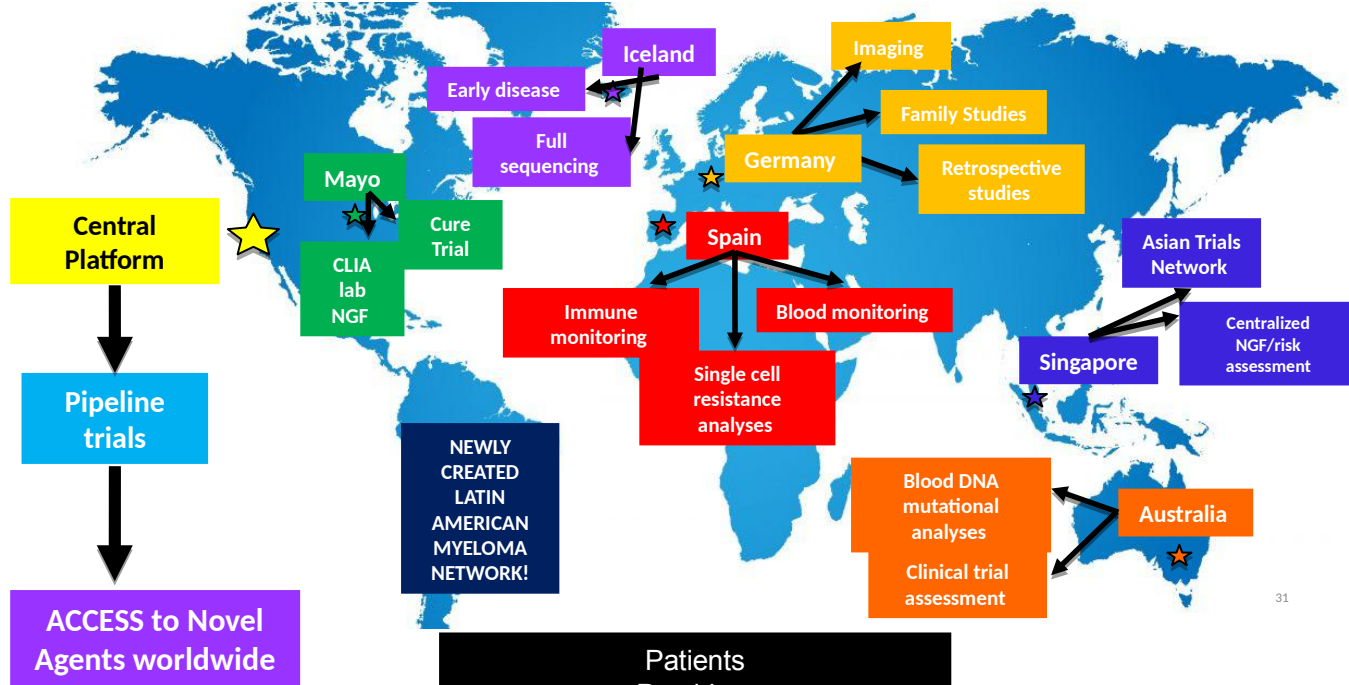


# Summary

- Diversity, Equity and Inclusion are critical concepts that will further influence our world
- The disparity in myeloma care is pronounced in the African American population, but also exists in many other groups
- The IMF has a longstanding history of commitment to these issues and has an integrated initiative in improve the disparity and induce needed change
- Success will be dependent on efforts at multiple levels, especially at the grass roots level of support groups

# IMF Global Presence

Primary Goal is to cure Myeloma



**THANK YOU!**

**Joseph Mikhael, MD, MEd, FRCPC**

**Professor, Translational Genomics Research Institute (TGen)  
City of Hope Cancer Center**

**Chief Medical Officer, International Myeloma Foundation**

**Director of Myeloma Research and Consultant Hematologist,  
HonorHealth Research Institute**

**[jmikhael@myeloma.org](mailto:jmikhael@myeloma.org)**