



Myeloma Today

A publication of the International Myeloma Foundation

Key Takeaways from ASH 2021

What myeloma patients and caregivers need to know



Philippe Moreau, MD



Sigurður Y. Kristinsson, MD, PhD



Shaji K. Kumar, MD



María-Victoria Mateos, MD, PhD



Thomas G. Martin, MD



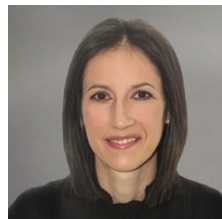
Brian G.M. Durie, MD



Hartmut Goldschmidt, MD



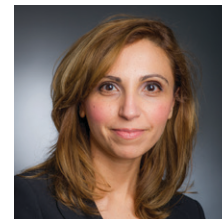
S. Vincent Rajkumar, MD



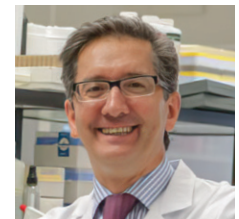
Noemí Puig, MD, PhD



Saad Z. Usmani, MD



Irene Ghobrial, MD



Jesús San-Miguel, MD, PhD



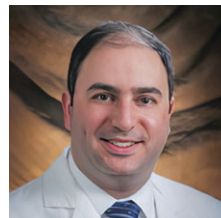
Sigrun Thorsteinsdottir, MD, PhD



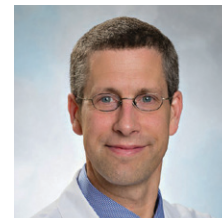
Sæmundur Rögnvaldsson, MD



Thorir Einarsson Long, MD, PhD



Dan Vogl, MD



Jacob Laubach, MD



Beth Fairman, PhD, CNP

Myeloma researchers and clinicians present exciting new data on the onset of myeloma, early evolution of the disease, diagnostics and biology, and more!

PAGE 4



63rd ASH[®] Annual Meeting and Exposition

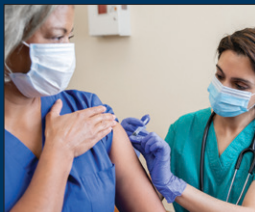
DECEMBER 11-14, 2021 • ATLANTA, GA • IN-PERSON/VIRTUAL

This edition of *Myeloma Today* is supported by
AbbVie • Amgen • Bristol Myers Squibb • Sanofi Genzyme • Takeda Oncology

Connect. Be Informed. Take Charge.

UPDATED AND INTERACTIVE RESOURCES AT A GLANCE

covid19.myeloma.org



The latest information on COVID-19 variants and vaccination for myeloma patients

diversity.myeloma.org



Diversity and inclusion are integral aspects of the myeloma community

infoline.myeloma.org



Contact the IMF InfoLine with your myeloma-related questions and concerns

medications.myeloma.org



Learn about FDA-approved therapies for myeloma

support.myeloma.org



Robin Tuohy rtuohy@myeloma.org will help you find a multiple myeloma support group

videos.myeloma.org



IMF Video:

Understanding CAR T-Cell Therapy video [Watch Now](#)

Ask Dr. Durie:

Are MGUS patients at higher risk of getting severely ill from COVID-19? [Watch Now](#)

Living Well with Myeloma:

IMF global research collaborations bring us closer to a cure for myeloma [Watch Now](#)

blogs.myeloma.org

Dr. Brian Durie's Week in Review:

Why understanding the COVID-19 omicron variant is important [Read Now](#)

publications.myeloma.org



- **Booklets** that explain myeloma therapies and more
- **Tip cards** on topics important to myeloma patients
- **Guide to Myeloma Acronyms and Abbreviations**
- **Guide to Myeloma Terms and Definitions**
- **Myeloma Today Fall 2021 edition**

Take advantage of the hyperlinks in *Myeloma Today* by signing up for the digital edition at subscribe.myeloma.org, where you can also sign up to receive alerts about IMF events, webinars, teleconferences, and advocacy actions, as well as our e-newsletter *Myeloma Minute*. And engage with us on social media!

A Message from the IMF Founder and the IMF Chairman

Dear Reader,

On November 12, 2021, the International Myeloma Foundation was pleased to announce that Yelak Biru, a longtime myeloma patient advocate, has been named IMF Chief Executive Officer.

Yelak was diagnosed with myeloma at the age of 25 while a student at the University of North Texas. Driven to learn more about the disease, he attended a local myeloma support group in Texas, which he later led, then founded and led a new support group in Arkansas. In 2015, Yelak joined the Board of Directors of the IMF, an organization he once turned to for guidance.

“Living with myeloma is not easy,” says Yelak, now a 26-year myeloma survivor. “But having an organization like the IMF beside me during my cancer journey has helped me live with – and not for – myeloma. I am looking forward to the fantastic opportunity of serving as CEO of the most consequential non-profit in the world and am grateful for the Board’s confidence in me. For over half of my life, I have been an advocate, volunteer, supporter, and fan of the IMF’s work and mission. As a myeloma patient, I have directly benefited from advances the IMF led and enabled. The IMF has significantly contributed to the research leading to the advancement of the science of myeloma. I believe the best is yet to come.”

We are confident that Yelak will put his talent and experience as a myeloma patient advocate to good use in leading the IMF, providing inspirational leadership in the pursuit of our vision to cure myeloma.

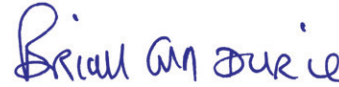
Yelak was born in Ethiopia. After earning undergraduate and graduate degrees in computer science from the University of North Texas, he worked in advanced business analytics at

PepsiCo. In 2017, he joined Walmart, where he worked in global technology. Yelak has participated in the National Institutes of Health (NIH) Council of Research Advocates and the National Cancer Institute (NCI) Myeloma Steering Committee, and has coauthored articles published in the *Journal of the National Comprehensive Cancer Network and Blood Cancer Discovery*. He appears frequently at international medical conferences. Yelak and his wife, Loul Haugs, live in Los Angeles.

Warm regards,



Susie Durie
IMF Founder
Director, Global Patient Initiatives



Dr. Brian G.M. Durie
IMF Chairman
Chief Scientific Officer



Susie Durie and Dr. Brian G.M. Durie receive a joint 2019 Honorary Doctorate for Scientific Excellence from the Vrije Universiteit Brussel



Yelak Biru, Susie Durie, and Dr. Brian G.M. Durie at the 2018 IMF Comedy Celebration



Loul Haugs and Yelak Biru

The IMF has moved!

INTERNATIONAL MYELOMA FOUNDATION
4400 Coldwater Canyon Avenue, Suite 300 – Studio City, CA 91604 USA
800.452.CURE (USA & Canada) 818.487.7455 (worldwide) TheIMF@myeloma.org myeloma.org

This free issue of *Myeloma Today*® (Volume 22, Number 1) is dated January 15, 2022. *Myeloma Today*® is a quarterly (Spring, Summer, Fall, and Winter) publication of the International Myeloma Foundation, located at 4400 Coldwater Canyon Avenue, Suite 300, Studio City, CA 91604 USA

Takeaways from ASH 2021

What myeloma patients and caregivers need to know

By Dr. Brian G.M. Durie
IMF Chairman & Chief Scientific Officer

I am very pleased to have this opportunity to share the exciting information from the 63rd Annual Meeting & Exposition of the American Society of Hematology (ASH) that took place in December 2021. Of the 4,140 abstracts presented at ASH, 879 were related to myeloma, many of which presented new data with important developments for the myeloma community.

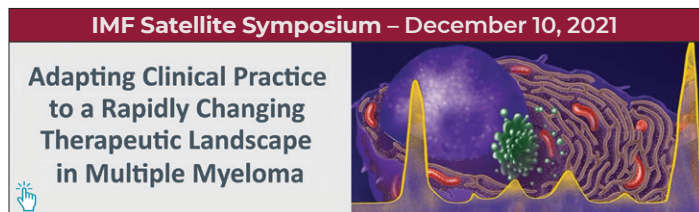
For the first time in my memory, the major abstracts did not necessarily relate to new treatments, but rather addressed questions about the onset of myeloma, the early evolution of the disease, as well as diagnostics and biology. In my opinion, this was not only unusual for ASH, but also a very important aspect of the meeting.

Satellite Symposium

On December 10, preceding the start of ASH, the IMF held its traditional Satellite Symposium. The 2021 IMF Satellite Symposium was attended by 858 people, 211 who were present in person and 647 who joined virtually, and so the total attendance was very close to the years before the COVID-19 pandemic. The 2021 IMF Satellite Symposium faculty included Dr. Thomas G. Martin (University of California, San Francisco), Dr. Philippe Moreau (University Hospital Hôtel-Dieu, Nantes, France), Dr. S. Vincent Rajkumar (Mayo Clinic, Rochester, Minnesota), and Dr. Jesús F. San-Miguel (Universidad de Navarra, Spain).

As part of our Satellite Symposium, we outline the algorithms for each stage of the disease. If you have SMM, consider treatment or go into a clinical trial. If you've got active myeloma, start treatment. For the newly diagnosed patient who is not a transplant candidate, we have two major treatment options. For autologous stem cell transplant (ASCT) candidates, the big question is VRd plus/minus Darzalex® (daratumumab), although I would say to maybe look into the future with the data on CAR T cells. Instead of ASCT, we should be thinking of using these amazing CAR T cells earlier in the disease as a consolidation approach. In the relapsed/refractory disease setting, we're looking at different combinations.

The case-based presentations from the IMF Satellite Symposium – “Adapting Clinical Practice to a Rapidly Changing Therapeutic Landscape in Multiple Myeloma” – are available for replay at [videos.myeloma.org](https://www.videos.myeloma.org) along with the accompanying slides and commentary. I encourage you to take advantage of these resources.



International Myeloma Working Group

On December 11, the IMF hosted a breakfast for members of the International Myeloma Working Group (IMWG), which begins at 6:30 a.m. but still draws many attendees. This time, there were more than 350 myeloma physicians and researchers who were able to participate: 120 “live” plus 230 virtually. Keep in mind that this meeting started at 3:30 a.m. Los Angeles time, where the IMF headquarters are located!

On December 13, the IMWG Conference Series, “Making Sense of Treatment,” focused on the latest myeloma-related news from the ASH conference, covering a number of important topics:

- A new look at early disease
- Minimal residual disease (MRD) monitoring
- Frontline therapy with 4-drug combinations
- Immune therapies, including CAR T and bispecifics
- Emerging new treatments

Panelists included Dr. Thomas Martin, Dr. María-Victoria Mateos (University of Salamanca, Spain), and IMF Nurse Leadership Board Member Beth Faiman, PhD (Cleveland Clinic, Taussig Cancer Institute). You don't want to miss this lively discussion on the forefront of the future of myeloma research and care! I encourage you to view the video recording and to download the accompanying slides from the IMF website.



Six iStopMM abstracts

A key part of the IMWG Breakfast is that we preview the ASH abstracts, selecting what we think are some of the most important presentations for myeloma. It was quite surprising that the IMF's iStopMM (Iceland Screens Treats or Prevents Multiple Myeloma), a population-based screening study for monoclonal gammopathy of undetermined significance (MGUS), was the top abstract at ASH! I am a co-author on this abstract and personally involved with this project. The iStopMM team, led by Dr. Sigurður Y. Kristinsson (University of Iceland, Reykjavík), is very active and submitted 6 abstracts to ASH. When we heard that one of our abstracts was accepted as an oral presentation, we were quite excited. But then we were notified that a second abstract was

accepted, and then a third, and then a fourth, and then it kept on going! The next two iStopMM abstracts were accepted as poster presentations.

It was gratifying that iStopMM was such a priority at ASH 2021. This project looks at the population of Iceland, where everyone over the age of 40 was invited to participate in the study and more than half of this population volunteered. There was a tremendous enthusiasm to take part in the project. Many diverse outcomes from iStopMM are possible as we can study different things at once, and this will benefit not only Iceland but the myeloma community around the world!

More than 75,000 individuals in Iceland had their blood tested and 3,725 were found to have a monoclonal protein in the serum. Bone marrow testing was carried out in over 1,500 people. In total, 180 individuals were diagnosed with smoldering multiple myeloma (SMM) or myeloma. Here is a capsule summary of iStopMM abstracts, with links to relevant interviews on the IMF website and to the ASH abstracts:

Abstract 156 addresses screening and identification of monoclonal proteins early: population-based screening versus chance detection at other medical check-ups can lead to much improved outcomes. The precise value of detailed testing and early intervention will be evident from comparisons in the three arms of the randomized clinical trial. If screening for monoclonal proteins becomes the standard of care, this changes the whole structure of myeloma care.

Abstract 151 shows for the first time that the prevalence of SMM is 0.5% in persons 40 years or older. The high prevalence of SMM has implications for future treatment policies as treatment initiation at the SMM stage is likely to be included in guidelines soon. This also underlines the necessity for accurate risk stratification.

Prevalence of Smoldering Multiple Myeloma: Results from the Iceland Screens, Treats, or Prevents Multiple Myeloma (iStopMM) Study

Sigrun Thorsteinsdottir, MD
University of Iceland
Reykjavik, Iceland

Abstract 154 demonstrates that while myeloma patients have an increased risk of severe COVID-19 disease when infected with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), individuals with MGUS were not associated with SARS-CoV-2 susceptibility or COVID-19 severity, which I think is rather good news. These findings suggest that immunosuppression in MGUS differs significantly from that of myeloma.

MGUS and COVID-19: Results from the Population-Based Iceland Screens Treats or Prevents Multiple Myeloma Study (iStopMM)

Sæmundur Rögnvaldsson, MD
University of Iceland
Reykjavik, Iceland

Abstract 542 shows that current reference intervals for serum free light chains (FLC) and FLC ratio are inaccurate for patients with decreased kidney function. This study proposes new reference intervals for serum FLC and FLC ratio for a more accurate diagnosis of MGUS in individuals with kidney dysfunction.

Defining New Reference Intervals for Serum Free Light Chains in Individuals with Reduced Kidney Function: Results of the Population-Based on Iceland Screens Treats or Prevents Multiple Myeloma (iStopMM) Study

Thorir Einarsson Long, MD
University of Iceland
Reykjavik, Iceland

In addition to the four oral presentations above, two iStopMM abstracts were presented as posters:

Abstract 2645 is the first study to evaluate and illustrate the role of monitoring circulating tumor plasma cells (CTPC) by next-generation flow (NGF) cytometry in patients with MGUS or SMM, finding that detection by the minimally invasive blood sampling is lower than has been previously reported.

Monitoring of Circulating Tumor Plasma Cells in Patients with Precursor Conditions of Multiple Myeloma: Data from the Prospective Iceland Screens, Treats, or Prevents Multiple Myeloma (iStopMM) Study

Jón Þórir Óskarsson, MSc
University of Iceland
Reykjavik, Iceland

Abstract 1618 highlights the importance of screening studies to evaluate the true epidemiological and biological implications of MGUS, suggesting selection bias in prior studies. Individuals with clinical MGUS are 1.5 to 3.3 times more likely to suffer from arrhythmias, chronic kidney diseases, endocrine disorders, heart failure, neurological diseases, and rheumatological diseases.

Estimating Selection Bias in Previous MGUS Research – the Importance of Screening: Results from the Population-Based Screening Study iStopMM

Aðalbjörg Ýr Sigurbergisdóttir, BSc
University of Iceland
Reykjavik, Iceland

Overall, the notable presence of the iStopMM research at ASH represents quite a tour de force by the Icelandic team led so ably by Dr. Kristinsson. No doubt, much more is to come in the next few years as other iStopMM results emerge.

Key study from Spain

Abstract 541 presents a very important study from Spain that screened over 5,000 patients using NGF immune testing to investigate the clinical significance of circulating tumor cells (CTCs) in patients with SMM, newly diagnosed MM (NDMM), and

(continues on next page)

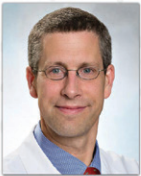
ASH HIGHLIGHTS – CONTINUED FROM PAGE 5

relapsed/refractory MM (RRMM). It turned out that checking the blood can be very precise about the level of CTCs, and this is very promising for now and for the future. This is a very important practical tool to classify patients.

Treatment results

Abstract 79 presents important treatment results from the GRIFFIN clinical trial, an updated analysis after 24 months of maintenance. The comparison of 3-drug (“triple”) versus 4-drug (“quad”) combination therapies has been a very topical question, and the role of quads in the frontline setting depends in part on the ongoing follow-up results in this trial.


Daratumumab Plus Lenalidomide, Bortezomib, and Dexamethasone (RVd) in Patients with Transplant-Eligible Newly Diagnosed Multiple Myeloma : Updated Analysis of GRIFFIN after 24 Months of Maintenance



Jacob Laubach, MD
Dana-Farber Cancer Institute
Boston, MA, USA

Abstract 84 presented final overall survival data from the BELLINI study, a phase III clinical trial of venetoclax or placebo in combination with Vd in relapsed/refractory myeloma. The addition of venetoclax to Vd showed significantly improved progression-free survival (PFS) in patients with t(11;14) or high BCL2, but resulted in increased mortality versus placebo in the total population.

Final Overall Survival Results from BELLINI, a Phase 3 Study of Venetoclax or Placebo in Combination with Bortezomib and Dexamethasone in Relapsed/Refractory Multiple Myeloma



Shaji Kumar, MD
Mayo Clinic
Rochester, MN, USA

Bispecific monoclonal antibodies


Several abstracts reporting the results of clinical trials with bispecific monoclonal antibodies (bispecifics) collectively indicate the potential for bispecifics. **Abstract 821** reported good outcomes for triple-class refractory patients. **Abstract 161** illustrated the excellent results with talquetamab. **Abstract 896** presented promising follow-up with teclistamab. **Abstract 157** showed clinically meaningful follow-up results with cevostamab. All these encouraging results point to an emerging role for bispecifics in myeloma.

Other important studies

Abstract 549 presented updated results of the CARTITUDE-1 clinical trial of ciltacabtagene autoleuvel (cilta-cel) in relapsed/refractory myeloma. At a longer median follow-up of 18 months, a single cilta-cel infusion led to early, deep, and durable

responses in heavily pre-treated myeloma patients. The remarkable findings included the deepening of responses over time, with more than 98% of patients ultimately responding to therapy. Cilta-cel demonstrated a manageable safety profile with no new safety signals observed. Follow-up is continuing and additional studies are ongoing in earlier lines of therapy and in outpatient settings.


Updated Results from CARTITUDE-1: Phase 1b/2 Study of Ciltacabtagene Autoleuvel, a B-Cell Maturation Antigen-Directed Chimeric Antigen Receptor T Cell Therapy, in Patients With Relapsed/Refractory Multiple Myeloma



Thomas Martin, MD
UCSF Helen Diller Family
Comprehensive Cancer Center
San Francisco, CA, USA

Abstract 2738 by Dr. Saad Usmani (Memorial Sloan Kettering Cancer Center, New York) presented preliminary data from the DREAMM-9 phase I clinical trial of Blenrep® (belantamab mafodotin) in patients with transplant-ineligible newly diagnosed myeloma. Blenrep + VRd did not reveal new safety issues and demonstrates high response rates. This is a unique study in the frontline setting and the early data are quite good.


DREAMM-9: Phase I Study of Belantamab Mafodotin Plus Standard of Care in Patients with Transplant-Ineligible Newly Diagnosed Multiple Myeloma



Saad Usmani, MD
Memorial Sloan Kettering Cancer Center
New York, NY, USA

Abstract 152 presents the first results of the PROMISE study, which was launched in 2019 and is the first nationwide US screening study for individuals at high risk of myeloma. The prevalence of MGUS has not been previously described in Black/African American individuals or first-degree relatives of patients with hematologic malignancies. The interim screening data on the first 2,960 participants over 40 years of age aims to characterize clinical variables of individuals who screen positive.

High Prevalence of Monoclonal Gammopathy in a Population at Risk: The First Results of the PROMISE Study




Irene Ghobrial, MD
Dana-Farber Cancer Institute
Boston, MA, USA

Abstract 1829 reports updates on the CESAR clinical trial. The results suggest that early treatment with intention to abrogate risk of progression in transplant candidate high risk smoldering myeloma patients is associated with a 94% PFS and overall

survival (OS) of 95% at 55 months and a sustained minimal residual disease (MRD) negative rate at 1 year post treatment of 67%.

Abstract 544 assesses treatment response by serum protein immunofixation (IFE), next generation flow (NGF) cytometry, and mass spectrometry coupled with liquid chromatography in the GEM2012MENOS65 clinical trial. It is important to explore alternative techniques that may be utilized in place of bone marrow aspiration in patients with undetectable disease.


Assessment of Treatment Response by IFE, Next Generation Flow Cytometry and Mass Spectrometry Coupled with Liquid Chromatography in the GEM2012MENOS65 Clinical Trial



Noemi Puig, MD
University Hospital of Salamanca
Salamanca, Spain

Abstract 898 on the phase I human clinical trial of modakafusp alfa (TAK-573), a first-in-class immunocytokine designed to deliver interferon alpha-2b (IFN α 2b) to CD38+ cells, has shown promising anti-myeloma activity in heavily pretreated patients, with an overall response rate of about 30%.

Modakafusp Alfa (TAK-573), an Immunocytokine, Shows Clinical Activity in Patients with Relapsed/Refractory Multiple Myeloma; Updated Results from a First-in-Human Phase I Study




Dan Vogl, MD
Abramson Cancer Center
University of Pennsylvania
Philadelphia, PA, USA

Abstract 463 presented the first primary endpoint of the GMMG-HD7 phase III clinical trial from Germany, which compares RVd with/without the CD38-mAb isatuximab with regard

to the rate of MRD negativity after induction therapy in patients with transplant-eligible newly diagnosed myeloma. To the best of our knowledge, this is the first study to demonstrate superiority of MRD negativity rates after induction by adding a CD38-mAb to RVd. This trial is ongoing.

Addition of Isatuximab to Lenalidomide, Bortezomib and Dexamethasone As Induction Therapy for Newly-Diagnosed, Transplant-Eligible Multiple Myeloma Patients: The Phase III GMMG-HD7 Trial



Hartmut Goldschmidt, MD
University Hospital Heidelberg
Heidelberg, Germany

COVID-19

A total of 10 abstracts presented at ASH addressed COVID-19, including iStopMM as discussed above, as well as **abstract 2719** presenting a Spanish study with follow-up data on 451 patients and demonstrating that although clinical severity has decreased over the first year of the pandemic in myeloma patients, mortality remains high with no change between the initial weeks of the pandemic and the following months. Prevention and vaccination strategies should be strengthened in this vulnerable population, particularly in those with active or progressive disease.

In closing

Despite the pandemic, ASH 2021 illustrated that an impressive amount of important myeloma research is continuing. I hope that you find the information I have shared to be useful. For a more detailed presentation, I invite you to view the video recording of the IMF's Best of ASH 2021 webinar at videos.myeloma.org and to download the accompanying slides. **MT**

 INTERNATIONAL MYELOMA FOUNDATION

The International Myeloma Foundation presents
Webinar Series

BEST OF ASH 2021

What Patients and Caregivers need to know

Duration: 60 minutes (including Q&A)

myeloma.org/videos/best-ash-2021-webinar



Brian G.M. Durie, MD
Chairman of the Board,
International Myeloma Foundation

#WHEREISDRJOE

M-Power Facebook Live

Studies on disparities in myeloma presented at ASH

By Dr. Joseph Mikhael
IMF Chief Medical Officer

The 63rd Annual Meeting & Exposition of the American Society of Hematology (ASH), held in December 2021, was an extraordinary platform for presentations of groundbreaking research in myeloma: impressive screening programs, quadruplet therapies in frontline therapy, and several new agents in relapsed disease. In addition to this great research, there were more than 20 abstracts devoted to disparities in myeloma.

On December 15, the IMF hosted a Facebook Live event to present an overview of the key ASH 2021 abstracts devoted to disparities in myeloma, and you can listen to the recording at mpower.myeloma.org. As we shine a spotlight on health equity in the United States and beyond, I would like to highlight for you some of the key themes that emerged from this important work.

Myeloma patients of African descent

Myeloma is twice as common in patients of African descent. Furthermore, despite great advances in the treatment of myeloma and improvements in overall survival, outcomes in African Americans remain inferior to myeloma patients who are white. However, we know that survival in African American patients can be superior when given equal access to therapies.

Understanding the reasons for this disparity is one of the key areas of work presented at ASH. Indeed, most of this research has focused on “diagnosing” the problem. Thus far, only a few studies propose a solution.

Difference in biology

Previous studies have shown that African Americans have differences in the biology of myeloma. They are diagnosed on average 5 years younger, are more likely to have the standard-risk cytogenetic feature of t(11;14), and are less likely to have the high-risk cytogenetic feature of deletion 17p.

The PROMISE clinical trial ([ASH abstract 152](#)) was a large screening study that showed us that 10% of African Americans over the age of 40 have monoclonal gammopathy of undetermined significance (MGUS), and the percentage may be even higher with more sophisticated testing techniques. [Abstract 402](#) added to our understanding by noting differences in mutation profiles in African Americans. Interestingly, in [abstract 4121](#) they propose that historical risk stratification with cytogenetics may not be as influential in African American patients.

Socioeconomic status

Several studies identified the link between socioeconomic status and outcomes in myeloma. The concept of financial toxicity was presented in [abstract 4027](#). Another study noted

the differences between patients who had access to WiFi to conduct video visits with their doctors during the pandemic versus those who held phone visits. African Americans are less likely to be able to have video visits, and this “digital divide” further exacerbates issues of structural racism and health inequity.

Access to testing and treatment

A plethora of studies identified the challenge in access to health-care in myeloma. Blacks are less likely to have the full testing needed ([abstract 4116](#)) and less likely to have access to novel treatments ([abstract 4118](#)).

Minority enrollment in clinical trials remains a major issue, especially in “pivotal” studies that often lead to drug approval by the FDA ([abstract 846](#)). Another study demonstrated reduced access to CAR T-cell therapy in African Americans ([abstract 566](#)). An important Canadian study noted that although Blacks had the same benefit from the use of Darzalex® (daratumumab), they were more likely to receive it later in their disease course than white patients ([abstract 1965](#)).

Strategies for testing and therapy

A minority of studies proposed solutions to the above problems, such as using a more inclusive prognostic score ([abstract 3789](#)) or using real-world data to identify communities where studies should take place to enhance access to clinical trials in minority populations ([abstract 3008](#)).

I applaud this work. To drive solutions, we need to understand the disparity more fully. Part of the solution may involve genuinely rethinking our approach to the diagnosis of myeloma, its therapy, and where and how we conduct clinical trials. It will also involve a partnership between all stakeholders, including policymakers, communities, healthcare providers, and regulators. The IMF is deeply committed to this issue. We have implemented our M-Power program, designed to empower patients and their communities to change the course of myeloma – a course, confirmed by the research above, that remains unacceptable.

More than 150,000 people have engaged in our program at mpower.myeloma.org and accessed the resources we make available to all. Join us. If we work together, we can make a difference in reducing the disparity in myeloma. **MT**

Please contact the IMF InfoLine for help with your myeloma-related questions and concerns. Phone lines are open 9 a.m. to 4 p.m. (Pacific) Monday through Friday at 800.452.CURE in the US and Canada or 818.487.7455 worldwide. You can also email InfoLine@myeloma.org to submit your query electronically.

Patients are Represented at ASH 2021

Support group leaders join medical meeting live online

By Robin Tuohy
IMF Vice President, Support Groups

In December 2021, the IMF brought together Support Group Leaders and patients to represent the myeloma community at the 63rd annual meeting of the American Society of Hematology (ASH). This has been an IMF tradition for many years and, despite the COVID-19 pandemic, ASH 2021 was as exciting a convergence of myeloma researchers and clinicians as ever. Doctors from around the world gathered online or in person to learn from the 879 myeloma-related abstracts. To learn the key takeaways from ASH in this edition of Myeloma Today, please read the articles by Dr. Durie (page 4) and Dr. Mikhael (page 8).

The IMF's team of patient leaders and advocates shared updates from ASH via Twitter (#ASH21 and #IMFASH21), Facebook, videos, and informative blogs that share their unique perspectives as patients, care partners, nurses, and Support Group Leaders. To the right are excerpts of their insights from this important meeting.

The IMF thanks our ASH 2021 Support Group Leader Team for the care, commitment, and service to the global myeloma community. In turn, these Leaders express their thanks to Dr. Brian G.M. Durie and Susie Durie, and to the IMF's industry partners who supported their attendance at ASH: Bristol Myers Squibb, Karyopharm Therapeutics, and Takeda Oncology. **MT**

Support Group Leaders Team blog excerpts

*ASH 2021 inspired me and stoked my fire... Topics that I feel are ones to provoke **deep thought and subsequent action**. As an oncology nurse, my focus always seems to be the patient's quality of life. This is not to say that the scientific research, new data, amazing advancements, and hard work that the 879 myeloma-related abstracts aren't of utmost importance – they are, and they will continue to guide the future of research in myeloma for years to come.*

*The research on SMM is important and valuable. To me, it provides a sense of **hope and optimism** – two things that can sometimes be in short supply when dealing with the gray area of smoldering myeloma.*

*Myeloma is a complex and dynamic diagnosis. Staying abreast of the most relevant information is challenging, and ASH is the most **informative** "one stop shop" to gather cutting-edge news. Helping each other understand what has been said and what it means makes this a well-rounded experience.*

*Listening to myeloma experts from across the globe means connecting with people who are **committed to finding a cure**. We anticipate hearing from them, year after year, as their research progresses. Even though we don't know them personally, we start to develop a connection to them. We are united by the common thread of myeloma.*



Robin Tuohy



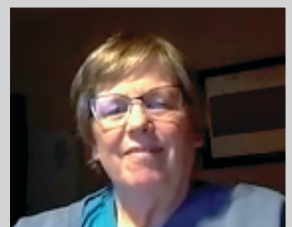
Sheri Baker



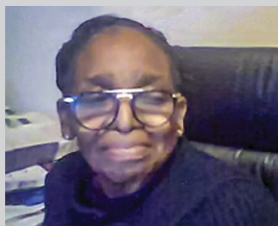
Yelak Biru



Becky Bosley



Jessie Daw



Gail G. McCray



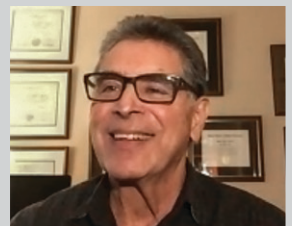
Linda Huguelet



Sue Massey



Teresa Miceli



John DeFlice, MD



Michael Tuohy



Jill Zitzewitz, PhD



Jack Aiello



MYELOMA
SUPPORT GROUP
LEADERS

#IMFASH21 Team

Read the Support Group Leader blogs  ash2021blogs.myeloma.org

AMN Holds Three Ground-Breaking Events

The IMF Asian Myeloma Network holds its 5th annual Summit, a Master Class for doctors, and a patient forum

By Daniel Navid
IMF Senior Vice President, Global Affairs

The IMF Asian Myeloma Network held three ground-breaking events for the region, which took place on consecutive weekends in October 2021.

Inaugural AMN Patient Forum

On October 10, the inaugural AMN Patient Forum brought together myeloma patients and family members from throughout Asia. Due to continued COVID-19 restrictions, the Forum was convened in a live online format, anchored by a headquarters studio in Bangkok. More than 80 participants joined the Forum from additional studios in Beijing, Hong Kong, and Seoul, as well as from homes and offices across Asia.

Generous support from Amgen, Celgene/Bristol Myers Squibb, Glaxo Smith Kline, and Janssen Oncology was provided to the IMF for this event and follow-up activities, with support for the Beijing studio additionally provided by Beigene, CARSGen, Takeda-China, and Xian Janssen.

Chaired by Dr. Daryl Tan (Singapore), the Forum enabled local patient groups to present their activities and to learn from experiences elsewhere.

Nerysa Lee of the Hong Kong Myeloma Care & Share patient association provided the keynote presentation with an overview of the work of her vibrant organization and an emphasis to explain the steps taken for its rapid development.

Robin Tuohy (IMF Vice President, Support Groups) spoke about how the IMF works to support myeloma patient groups and explained the IMF "Tool Kit" that offers IMF services to fledgling myeloma societies in Asia.

Reports from independent patient groups in each of the eight AMN countries and regions – China, Hong Kong, Japan, Korea, Malaysia, Singapore, Taiwan, and Thailand – showed different stages of activities, with all intending to move ahead with increased action for patient education and support, and advocacy efforts. Hitherto loosely organized groups in Malaysia, Singapore, and Thailand indicated the intention soon to launch formal myeloma associations.

Educational resources will be provided by the AMN to assist the various local societies. Significantly, the societies also offered to work together. For example, the Hong Kong association offered to provide Chinese language patient information materials to their counterparts in China, Taiwan, Singapore, and Malaysia.

A second AMN Patient Forum is being planned for October 2022 in Singapore, when follow-up activities will be reviewed.

Inaugural AMN Master Class

On October 17, the AMN held its inaugural Master Class in a live a live online format. Anchored by a headquarters studio in Bangkok, the Master Class included over 115 participants, joining from additional studios in Beijing, Hong Kong, Singapore, and Seoul, as well as from homes and offices across Asia.

Generous support was provided to IMF for this event by Amgen, Antengene, Glaxo Smith Kline and Sanofi Genzyme, with support for the Beijing studio additionally provided by Beigene, CARSGen, Takeda-China, and Xian Janssen.

Co-chaired by Dr. Brian G.M. Durie (IMF Chairman) and Dr. Wee Joo Chng (Singapore), the AMN Master Class was an educational experience for invited young hematologists from Asia. Along with Drs. Durie and Chng, the Master Class faculty included renowned myeloma experts Dr. S. Vincent Rajkumar (USA) and Dr. Thomas Martin (USA), as well as AMN members Dr. Masahiro



Abe (Japan) and Dr. Kihyun Kim (Korea). Faculty members delivered presentations on the current standard of care in myeloma at the global level, followed by practical approaches to myeloma management in Asia.

In addition to question-and-answer sessions, the Master Class included a panel discussion on future treatment options in Asia, featuring AMN members Dr. Wenming Chen (China), Dr. James Chim (Hong Kong), Dr. Jeffrey Huang (Taiwan), Dr. Kazuyuki Shimizu (Japan), and Dr. Daryl Tan (Singapore).

The course concluded with an exam reflecting the detailed information from the presentations. Participants were able to take the test electronically. It was gratifying to see that all the participants completed the exam successfully, and all received a certificate of achievement after the course.

A second AMN Master Class is being planned for October 2022 in Singapore, including a visit to a myeloma center for hands-on instruction.

Fifth AMN Summit

On October 23–24, AMN's 5th annual Summit was held in a live online format, anchored by a headquarters studio in Bangkok. More than 150 participants joined from additional studios in Beijing, Hong Kong, Seoul, and Singapore, as well as from homes and offices across Asia.

Generous support was provided to IMF for this event by Platinum-level partner Sanofi Genzyme, Gold-level partners Binding Site and Janssen Oncology, Silver-level partners AbbVie, Amgen, and Glaxo Smith Kline, and Local-level partners Celgene/Bristol Myers Squibb (for the Singapore studio) and Beigene, CARSGen, Takeda-China, and Xian Janssen (for the Beijing studio).

The Summit, co-chaired by Drs. Durie and Chng, provided the opportunity for leading Asian myeloma experts to review recent developments in the myeloma field and identify areas for action in the coming year.

On the first day, presentations provided by myeloma experts included: frontline therapy (Drs. Rajkumar and Abe), minimal residual disease (Drs. Bruno Paiva, Chen, and Stephen Harding), immune therapies (Drs. Martin and Chng), and relapsed myeloma (Drs. Jean-Luc Harousseau and Kim).



On the second day, the following standing AMN Committees reported on their findings: 1) Clinical Priorities in Asia (Drs. Chng and Jae Hoon Lee; 2) High-Risk Treatment (Drs. Chim and Huang); 3) AMN MRD Subcommittee (Drs. Chen and Suporn Chuncharunee); 4) Launching CART-Cell Trials in Asia (Drs. Martin and Juan Du; and 5) Asian Patient Support (Drs. Tan and Shimizu). In all cases, recommendations were presented for further AMN projects, including the next steps for the launch of the AMN virtual Tissue Bank, new clinical trial projects targeting high-risk myeloma and using new immune therapies, work to harmonize MRD detection, and follow-up to the recent AMN Patient Forum.

The second day of the Summit, Dr. Chng reviewed ongoing AMN clinical trial projects and Dr. Chandramouli Nagarajan reviewed pending proposals for additional projects. Clinical trials have been a highly successful area of AMN's work, both in providing important research data as well as providing the means for Asian patients to access novel therapies not otherwise yet available.

Finally, as in prior years, the Summit turned attention to "A Look to the Future" with Dr. Durie providing insights about the direction of myeloma treatment and potential cure globally, and with Dr. Tan providing an Asian perspective including a review of access issues.

The 6th AMN Summit is being planned, hopefully as an in-person event, in Singapore from October 14–16, 2022. **MT**



The AMN is the first network of its kind in the region, and it has taken the lead in projects to assist the IMF in providing physician education and patient support throughout Asia. Myeloma is a growing health problem in Asia, with an incidence that is approaching that in Western countries, but with a much larger population base. Visit amn.myeloma.org for more information.

1. Daniel Navid
2. Dr. Daryl Tan, Dr. Thomas Martin, and Dr. Wee Joo Chng
3. (top row) Dr. Jae Hoon Lee and Dr. Juan Du; (middle row) Dr. James Chim and Dr. Wenming Chen; (bottom row) Dr. Jeffrey Huang and Dr. Masahiro Abe
4. Dr. Brian G.M. Durie
5. Dr. S. Vincent Rajkumar, Dr. Suporn Chuncharunee, and Li Leng and Paul Chan
- 6-8. IMF headquarters studio in Bangkok, Thailand

GMAN Webinar at ASH 2021

Member organizations gather for a successful virtual meeting

By Serdar Erdoğan
IMF Director, GMAN and European & Middle Eastern Patient Programs

On December 15, 2021, representatives of GMAN member organizations gathered to hear about upcoming myeloma therapies and other news from ASH 2021. Nearly 30 representatives of the global myeloma community dialed in for the 2-hour webinar, held in place of the traditional in-person meeting. The webinar included inspirational developments in global research by the IMF.

Dr. Brian G. M. Durie (IMF Chairman) and Susie Durie (IMF Founder) welcomed a truly global community dialing in from as far afield as Finland, Switzerland, across the United States, and even Australia at 5:00 in the morning!

Susie Durie welcomed the participants and shared the exciting news that long-term GMAN member Yelak Biru now serves as the IMF's Chief Executive Officer. Yelak is a dynamic patient advocate and has served on the IMF's Board of Directors since 2015.

The webinar agenda included an update on key abstracts at ASH, an update on the 2022 Susie Novis Durie Educational Grants, and a review of 2021 GMAN patient education webinars.

Dr. Durie provided a comprehensive summary of highlights from ASH, where 879 myeloma-related abstracts were presented. There was much exciting data from the iStopMM (Iceland Screens Treats or Prevents Multiple Myeloma) research study where 75,000 individuals have already been screened for the earliest signs of myeloma. The iStopMM data included 6 abstracts (4 oral presentations and 2 poster presentations). This is the largest clinical trial ever conducted of this nature. Abstract #151 reported an unexpectedly high prevalence of

smoldering multiple myeloma (SMM), demonstrating an incidence of 0.5% in people over 40 years of age, which supports the importance of screening.

One key highlight from abstract #549, an update of the phase Ib/2 CARTITUDE-1 clinical trial in relapsed or refractory myeloma patients, where T-cells are removed and engineered, then re-administered in a "one and done" process, was the overall response rate (ORR) of 97.9%! "This is amazing, with a deepening response over time," said Dr. Durie, "Data shows 67% median response at one year and 83% median response at 2 years follow-up."

There was some exciting data in abstract #898, an early phase I study of an immunocytokine molecule modakafusp mlfa (TAK-573), with encouraging response rates. Abstract #84 described an immunotherapy molecule REGN5458, with response rates almost doubled compared to single-agent treatment.

Susie Novis Durie Educational Grant

Three inspiring presentations from 2021 recipients in Austria, Israel, and Portugal highlighted the importance of GMAN support to its member organizations.

Elfi Jirsa reported on a program in Austria to support a greater quality of life by increasing movement and activity. Thousands of participants join a regular online program that is free to attend and supported by Professor Richard Crevenna and Philipp Jelinek, the famous Austrian triathlete and television presenter. In addition, more than 17,000 participants joined a symposium in October. In addition, more than 17,000 individuals have benefited from a symposium held in October 2021 that continues to be available for free at myelom-lymphoma.at.



Varda Shoham from Israel's AMEN organization introduced a program to support the Arabic population that represents almost a quarter of local myeloma patients. The project aims to raise awareness amongst patients, caregivers, and physicians. Materials are translated into Arabic, including on a Facebook page for Arabic patients, and simultaneous translation into Arabic language is made available at medical conferences.

The Portuguese Association against Leukaemia (APCL) was represented by Lara Cunha. The development of a new tool to support patients and caregivers convened a multidisciplinary team that includes a psychologist and physiotherapist. The launch is expected in February 2022.

Patient meetings

Despite the pandemic, GMAN member organizations maintained an active seminar calendar during Fall 2021. Below are just three examples of such activities. Other myeloma patient education meetings were also held.

On October 22, the Myelom-Lymphom Hilfe Österreich group hosted a seminar in Austria with attendees also joining online from Germany and Switzerland. Elfi Jirsa, President of Myelom-Lymphom, opened the meeting that featured Prof. Dr. Heinz Ludwig, Prof. Richard Crevenna, Prof. Peter Neumeister, Dr. Thomas Nösslinger, and Dr. Veronika Lang. Phillip Jelinek (Romy Prize winner, triathlete, and fitness coach) demonstrated an exercise session that has since been watched by more than 4,000 individuals!

On October 23–24, Ceska Myelomova Skupina and Klub Pacientu Mnohocetny Myelom held a webinar in Czechia with 110 myeloma patients and caregivers attending virtually. Faculty included Prof. Roman Hajek, Dr. Vladimír Maisnar, Dr. Jakub Radocha, Dr. Alexandra Jungova, and Dr. Jiri Minarik. Alice Onderkova and Petr Hylena reported on meetings and activities in both Czechia and Slovakia.

On November 11, Icelandic myeloma patient organization Perluvinir held a webinar that was attended by 40 patients, including several who joined online while in hospital.

Susie Durie opened the webinar with moderator (and myeloma patient) Kjartan Gunnarsson. Faculty included Dr. Durie, Dr. Sigurður Kristinnsson, Dr. Sæmundur Rögnvaldsson, and nurse Halla Gretarsdottir. This was the first Perluvinir webinar with attendees from three continents!

Action and awareness

Peter Anton (IMF Vice President, Marketing) gave an update on the 2021 March Myeloma Action Month (MAM). This included the Wall of Resilience showing activity from a successful multi-channel approach in more than 36 countries using the hashtag #IAMRESILIENT2021.

Peter also shared highlights of the 2021 Blood Cancer Awareness Month (BCAM), which took place in September, including the use of a new channel aimed at younger patients, Twitch. The campaign had a remarkable impact of over 10 million hits using the #KnowMyeloma hashtag.

In 2022, the focus is all about ACTION! We look forward to supporting this and to learning about the positive impact for our community at a future meeting.

In closing

To bring the webinar to a close, Dr. Durie gave an update on COVID-19. He reminded us of the importance for myeloma patients to be fully vaccinated and boosted if possible. He also advised us to beware of asymptomatic spread and to be especially careful when traveling. It is important to look after ourselves and work on resilience. There are useful and up-to-date IMF videos and materials, including Dr. Durie's blogs, always available at myeloma.org.

Dr. Durie thanked everyone for their engagement and support, including our sponsors without whom this would not have been possible: Bristol Myers Squibb, GSK, Oncopeptides, Sanofi Genzyme, and Takeda Oncology. On behalf of GMAN we thank you all for your support of the global myeloma community! **MT**



Take Meaningful Action to Help Others

Turn YOUR ideas into progress toward a cure for myeloma!

By **Suzanne Battaglia**
IMF Senior Director, Member Events

What are your goals and resolutions for 2022? If doing something meaningful for others is on your list, then holding a myeloma fundraiser in your community just might fit the bill. In 2021, the fun and imagination displayed by members who raised funds for the IMF was truly inspiring!

Now, YOU can help the IMF keep that streak of compassionate creativity going by holding an event in 2022 to raise myeloma awareness and help support our search for a cure. Whether you're a first-timer or a veteran community fundraiser, the IMF team is here to help. Together, we can explore event ideas you might be considering, share our experiences about what works best, and offer support to help you create a successful event.

Despite the COVID-19 pandemic, IMF members raised funds while celebrating their milestones, running real races, and playing virtual games. They still got on their bicycles, took nature walks, and swam in the ocean. You, too, can keep doing what you love best while turning that activity into myeloma awareness and support for the IMF research and other programs.

I'm very optimistic that in 2022 we'll have more opportunities to spend time together in virtual and, hopefully, in safe but more 'traditional' ways. Connecting in the virtual realm has inspired our members to successfully fund four 2022 Brian D. Novis Research Grants, as well as numerous other IMF programs and services. (For information about the important myeloma research being funded in 2022, please stay tuned for the next edition of *Myeloma Today*.)

Here are just a few examples of successful events held in 2021:

- **Laughs 4 Life** comedy show, hosted by Kent Oliver and headlined by Nate Bargatze, was such a success that Kent and his wife Candace are funding their fifth myeloma research grant in 2022!
- **Angela Barto Memorial Golf Tournament** is the first major event hosted by Chad Barto and his teenage son in memory of wife and mom, Angela. The golf tournament raised enough funds to support a myeloma research grant!
- **Miles for Myeloma** was held as a virtual race in 2021. Participants from across the country joined in to become a part of something big. This will be the first IMF research grant funded by Miles for Myeloma.
- **13th Annual Czerkies Memorial Golf Outing** has been held since 2008 by the Czerkies Family as a tribute to their mom Carolyn, who passed away from complications of myeloma in 2000. Their dad Edward passed away in 2018 after a courageous fight with prostate cancer, and now the golf outing honors the memory of both parents. The Czerkies are funding their fifth myeloma research grant in 2022!

The IMF is here to help you plan your first or your next successful fundraiser. For those who are still appropriately cautious of potential exposure to the coronavirus, many events can be held in a virtual format or a distancing component can be added to an in-person event. The IMF can provide information on CDC recommendations and the safety measures that may be required in your state. We look forward to hearing from you! **MT**

Bring your fundraiser to fruition! Contact Suzanne Battaglia at sbattaglia@myeloma.org or 800-452-2873 ext. 227, and visit myeloma.org/take-action/fundraise to support events that benefit IMF programs and services.

Giving Tuesday

During the 2021 *Giving Tuesday* campaign in November, the International Myeloma Foundation shared stories of dynamic and endearing individuals who have given their time to the IMF and to the myeloma community at large.

The response was tremendous. By the end of the campaign on November 30, we surpassed our original goal of \$50,000 and reached \$60,000 in donations. Please meet the myeloma survivors who made our *Giving Tuesday* campaign a success, and help us keep the spirit of *Giving Tuesday* alive all year long!

donate.myeloma.org



Join the Fight Against Myeloma!

IMF research initiatives contribute to the search for a cure

By Lynn K. Green, Ed.D.
IMF Senior Vice President, Philanthropy

Six abstracts featured at the American Society of Hematology (ASH) annual meeting in December 2021 presented the work of the IMF's iStopMM® (Iceland Screens Treats Or Prevents Multiple Myeloma) initiative. This is impressive by any measure and has the potential to benefit patients with myeloma the world over. You can read more about this important project in the ASH article by Dr. Brian G.M. Durie on page 4 or on the IMF website myeloma.org.

iStopMM is just one of many innovative research projects led by the IMF. The quest for a myeloma cure demands constant innovation. With guidance from the world's foremost experts on myeloma, the IMF has created an arsenal of resources with the mission to find a cure. In this edition of *Myeloma Today*, we would like to share with you just a few examples of how the IMF's research initiatives are making an impact.

International Myeloma Working Group

In 2010, the IMF's [International Myeloma Working Group \(IMWG\)](#) held its inaugural summit in Spain, with nearly 70 of the world's leading myeloma experts gathered to chart the future of treatment and care. The IMWG now has more than 200 members worldwide and has generated critically important research, as well as important consensus guidelines.

A major premise of the IMF is bringing together top myeloma experts globally to eliminate redundancy through collaboration. This is extremely helpful in both validating study results and avoiding needless duplication when study results are clear. The research can be done in a more cost-effective way because redundancy is decreased.

Black Swan Research Initiative

In 2012, the IMF launched the [Black Swan Research Initiative® \(BSRI®\)](#), a unique project to develop the first definitive cure for myeloma. The BSRI is funding several "CURE" trials in the United States and abroad. These studies use a "curative strategy" that aims to treat myeloma early and aggressively. Our aim is to see patients restored to a normal, healthy life, free of myeloma.

The IMF was key in developing a highly sensitive and informative cytometry technique to detect myeloma. [Next-generation flow \(NGF\)](#) is currently used worldwide in real-world practices and is part of countless clinical trials that test drug efficacy.

The IMF was first to develop new methods that accurately test for [minimal residual disease \(MRD\)](#) to evaluate the depth of response of current myeloma treatment strategies. Evidence regarding the prognostic importance of MRD continues to grow rapidly, with MRD being incorporated in an increasing number of clinical trials, including as a primary endpoint and to guide

treatment choices. A correlation between MRD-negativity and survival has been established.

The BSRI team continues to take steps to achieve cure for patients who rapidly achieve MRD-negativity with currently available therapies. In addition, more than 40 BSRI projects are underway around the globe to study various aspects of residual disease.

iStopMM

In 2016, the BSRI launched [iStopMM](#), an unprecedented project with the ultimate goal of preventing myeloma before it develops. iStopMM aims to identify candidates for early treatment in myeloma by examining the potential benefit of screening for MGUS and smoldering myeloma.

To date, approximately 75,000 volunteers over the age of 40 have taken part. This makes iStopMM the largest population-based screening study for any type of cancer ever conducted. iStopMM is successfully identifying myeloma and its precursors among study participants. Because nearly all citizens of Iceland over age 40 undergo routine blood tests, the country is an ideal setting for this research, which will benefit myeloma patients around the world.

The study's leader, Dr. Sigurdur Kristinsson (University of Iceland), stated that "Understanding the epidemiologic, genetic, and immunologic factors that go along with an increased risk of myeloma's progression could open the door to early intervention efforts in high-risk patients and possible preventive strategies. This would improve overall survival and quality of life for patients worldwide."

"This extensive biobanking is enabling genetic and immune testing," said IMF Chairman Dr. Brian G.M. Durie. "Longer-term follow-up will not only yield groundbreaking data about the biology of early disease and the value of early diagnosis, but also shed light on the optimal interventions to achieve both prevention and a cure."

The work being done in Iceland is inherently important to IMF research in the United States. There is growing evidence that what is learned locally can be used to enhance understanding and treatment internationally, and vice versa. By maintaining a global perspective, redundancy can be avoided or limited, and emphasis is placed on emerging areas of priority.

YOU could play a vital role in the early detection and treatment of myeloma by becoming a philanthropic partner with the IMF. Join us in finding a cure for myeloma by making a philanthropic contribution today! MT

For more information, please contact Lynn Green at lgreen@myeloma.org or 1.334.332.0888.

Cancer Drug Parity Act Reintroduced

Patients must have timely access to their medications!

By Robin Levy
IMF Senior Director, Public Policy & Advocacy

The International Myeloma Foundation (IMF) Advocacy Team is continuing our ongoing discussions with legislators to address the specific issues of patients with myeloma. One such issue that we have been working on for many years is the importance of patients having access to affordable, uninterrupted orally administered cancer therapies. This has become even more pressing during the COVID-19 pandemic.

Oral parity legislation addresses this accessibility issue by ensuring that oral chemotherapy drugs, like many of the drugs taken by myeloma patients, are covered by insurers in the same way intravenous (IV) therapies are. Currently, most patients who are prescribed IV drugs are financially responsible for a *copay*, whereas most patients on orally administered therapies must pay *coinsurance* for their drugs. A copay is a set rate you pay for medication, doctor visits, and other types of care. Coinsurance is the percentage of costs for which you are responsible, and paying a percentage of the cost of oral drugs can be unaffordable for the patient who needs them.

The IMF has previously worked to pass laws that ensure that both types of drugs are treated equally by insurers at the state level. Due to these efforts, 43 states along with Washington, DC, have state-level laws addressing this issue. That said, federal legislation is still needed to help more than 130 million people with federally regulated insurance plans.

The IMF has been actively working to address this issue for those who do not benefit from the state bills. On July 9, 2021, H.R. 4385 was reintroduced in the House of Representatives and the Senate companion bill, S. 3080, was reintroduced on September 27, 2021. This legislation, known as the Cancer Drug Parity Act, has bipartisan support and would help many of the individuals not reached by the state level laws.

The bill had to be restructured due to political challenges, and the IMF led the efforts to rewrite the legislation and work with members of the Coalition to Improve Access to Cancer Care (CIACC) and Congressional leaders to ensure this process ran smoothly. Because the bill has been rewritten, our efforts to educate Members of Congress are even more important than ever. The bill does not have an impact on patients on Medicare, but this bill does benefit a large percentage of other patients with cancer.

We are thankful for those in Congress who are leading this issue; specifically, we wish to thank Rep. Brian Higgins (D-NY), Rep. Brett Guthrie (R-KY), Rep. Doris Matsui (D-CA), Rep. Gus Bilirakis (R-FL), Rep. Joseph Morelle (D-NY), and Rep. Glenn Grothman (R-WI) who are leading the bill in the House of Representatives. We also extend our gratitude to Sen. Tina Smith (D-MN) and Sen. Jerry Moran (R-KS) who are leading the efforts in the Senate. We are grateful to every Congressional supporter of this legislation and to their staff for understanding how impactful the passage of this bill would be for patients.

Please visit access2cancercare.org if you wish to read more about the bill, our efforts, and the CIACC. **MT**



Sign up for the IMF Advocacy Newsletter at subscribe.myeloma.org, learn more about our activities at advocacy.myeloma.org, and contact us at advocacy@myeloma.org. We welcome your ideas, questions, and engagement.

The Myeloma ACTION Team Needs YOU!

You can become an advocate for the myeloma community

Join the Myeloma ACTION Team, also known as "Advocates Committed To Inspiring Others Nationwide!" Our team works together to strengthen support for legislation, build strong grassroots networks, and raise awareness of issues that affect myeloma patients. You will receive training, provide input, and undertake actions to advance policies that will help myeloma patients.

Myeloma patients and caregivers like you have helped advocate for increases in cancer research funding, ensuring myeloma-specific research continues, oral drug parity, access to clinical trials, healthcare disparities, COVID-19-specific advocacy, and veterans' issues. Joining the Myeloma ACTION Team will give you the opportunity to address the issues that are directly affecting you.

YOU can make a difference!
advocacy@myeloma.org

Developing A Mental Survival Strategy

Tips for building and maintaining our resilience in 2022

By Dr. Brian G.M. Durie
IMF Chairman of the Board

As we adapt to a world in which we will be living with COVID-19 well into 2022 and beyond, it is important to develop a mental survival strategy. We must create a personal world in which we not only survive but prosper. The first step is to believe that this is possible, and then build programs for success. Small actions can make a big difference.

Healthy habits to follow

In a recent article, *New York Times* health columnist Tara Parker-Pope summarized “[Our Favorite Healthy Habits of 2021](#).” This roundup of the top eight suggestions can help us all live a little better as we move into 2022.

- **Best Hours:** Set aside your best hours to focus on personal goals. For many, this is early in the day. But for night owls it may be much later. Make this your time to recharge.
- **Exercise Snacks:** Instead of getting an extra cup of coffee or tea, get up and pace or climb the stairs or do jumping jacks. Short bursts of exercise are really healthy.
- **Take a Photo:** Capture something special each day. This may be your dog or a flower that has just started to bloom or the pattern of clouds in the sky. Share the photo with family and/or friends. This is known to increase happiness.
- **Check How You Feel:** Ask yourself honestly if you feel energetic or frazzled or really unsettled. By acknowledging this reality, you can set the stage for the day to get the most accomplished or get back on track if possible. This reality check is calming in itself.
- **Five-Finger Breathing:** Take time to breathe in and out as you move from finger to finger to create a sense of calm: a really simple meditation.
- **Make Things Easier:** Often, accomplishing planned goals is difficult. For example, if your goal is to eat more home-cooked meals, a meal-kit delivery service can remove a lot of the stress involved in making that happen.
- **Take A Mindfulness Break:** During the day, take a break. Some people find that watching the [jellyfish on the Monterey Bay Aquarium](#) webcam induces a meditative state. You may recall a similar recommendation I made to watch the [penguins from the Shedd Aquarium](#). Seeing these hilarious penguins visit Chicago’s Museum of Contemporary Art, baseball park, and other locations, will lighten your day – something we all need.
- **Find a Buddy:** Find someone to spend time with once or twice a week to walk, hike, or get some exercise. Getting out and about is a great tonic, both mentally and physically.



Take a “Forest Bath”

An amazing way to de-stress is a Japanese concept called “[Forest Bathing](#).” Dr. Qing Li, author of a [book](#) with this title, says the process can work well without a complete forest: a cluster of trees in the park is enough. Simply being in nature, literally bathing in the atmosphere of the trees, can certainly restore our mood and increase our vitality. Plants are a source of oxygen and the sounds of nature pull you away from the city. This is definitely better than rushing to the supermarket at the end of the day.

If a trip to the park isn’t in the cards, you can visit the [Mind and Body section of the IMF website](#), where myeloma patients can find wellness resources like breathing, relaxation, mindfulness meditation, and yoga exercises.

Staying safe

Staying safe continues to be important for all myeloma patients, especially if you are undergoing new treatment. So please:

- Get fully vaccinated and get your booster shot.
- Always wear a mask in all risk situations.
- Avoid or really, really limit travel.
- Continue to organize safe get-togethers with family and friends who are also fully vaccinated and have had a negative COVID test if they’ve engaged in any activities that carry risk of exposure.

Let’s move into 2022 with a positive attitude: our personal sanity will improve, and success will come our way. Although we need to track the negatives in the news, a focus on positive updates will help us all. Let’s enjoy and be grateful for, as my mother would always say, “small mercies” – the unexpected, good things that happen – and help the less fortunate whenever we can. **MT**

Dr. Brian G.M. Durie serves as Chairman of the International Myeloma Foundation and as Chairman of the IMF’s International Myeloma Working Group, a consortium of more than 200 myeloma experts from around the world. He also leads the IMF’s Black Swan Research Initiative®.

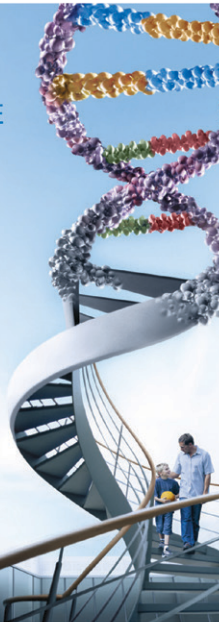


TRANSFORMING THE LANGUAGE OF LIFE INTO VITAL MEDICINES

At Amgen, we believe that the answers to medicine's most pressing questions are written in the language of our DNA. As pioneers in biotechnology, we use our deep understanding of that language to create vital medicines that address the unmet needs of patients fighting serious illness – to dramatically improve their lives.

For more information about Amgen, our pioneering science and our vital medicines, visit www.amgen.com

Amgen is a proud sponsor of the International Myeloma Foundation



©2020 Amgen Inc. All rights reserved.



Transforming patients' lives through science™

We are in the business of breakthroughs—the kind that transform patients' lives. Dedicated to our mission of discovering, developing and delivering life-saving innovations that help patients prevail over serious diseases, we'll never give up our search for more hope, for more people, around the world.



Visit bms.com to see how we're bringing a human touch to everything we do.

© 2021 Bristol Myers Squibb Company. All rights reserved.

OUR COMMITMENT TO PATIENTS WITH MULTIPLE MYELOMA IS

unwavering.
unshakable.
unbreakable.

Sanofi Genzyme is working tirelessly to ensure that patients with multiple myeloma can look ahead with newfound hope.

www.sanofigenzyme.com



© 2020 sanofi-aventis U.S. LLC. All rights reserved. SAUS.ONP.19.10.5229a 02/20



Better Health, Brighter Future

At Takeda Oncology, we endeavor to deliver novel medicines to patients with cancer worldwide through our commitment to science, breakthrough innovation and passion for improving the lives of patients.

We know that our mission is not a quick or simple one, but we are up for the task: **we aspire to cure cancer.**



ONCOLOGY

To learn more, visit us at takedaoncology.com.



©2019 Millennium Pharmaceuticals, Inc. All rights reserved.

YOU ARE NOT ALONE

Virtual Support Group for Multiple Myeloma Families!

This support group for myeloma patients and caregivers who have young children offers strength and inspiration through education, empathy, empowerment, and encouragement. Educationally supported by the IMF, this group meets online monthly.

For more information, please visit:
MMfamilies.support.myeloma.org



KNOWLEDGE IS POWER!

INTERNATIONAL MYELOMA FOUNDATION

Founder
Brian D. Novis

Founder
Susie Durie

Board of Directors

Chairman **Dr. Brian G.M. Durie**

Christine Battistini
Prof. Dr. Mario Boccardo
Loraine Boyle
Susie Durie
Martine Elias
George T. Hayum
Jason Katz
Benson Klein

Andrew Kuzneski, III
Dr. Robert A. Kyle
Prof. Dr. Heinz Ludwig
Dr. Edith Mitchell
Charles Newman
Dr. S. Vincent Rajkumar
Matthew Robinson
E. Michael D. Scott

IMF Executive Team

Yelak Biru
 Chief Executive Officer

Dr. Brian G.M. Durie
 Chief Scientific Officer

Jennifer Scarne
 Chief Financial Officer

Dr. Joseph Mikhael
 Chief Medical Officer

Diane Moran
 Senior Vice President,
 Strategic Planning

Lynn K. Green, Ed.D.
 Senior Vice President,
 Philanthropy

Lisa Paik
 Executive Vice President,
 Medical Affairs

Mimi Choon-Quinones, PhD, MBA
 Senior VP, Global Advocacy,
 Access, Policy & Research

Daniel Navid
 Senior Vice President,
 Global Affairs

Peter Anton
 Vice President, Marketing

IMF Staff

Betty Arevalo
 Inventory Control Manager

Karla Lemus
 Assistant to Senior Director,
 Member Events

Suzanne Battaglia
 Senior Director, Member Events

Robin Levy
 Senior Director,
 Public Policy & Advocacy

Nancy Bruno
 Regional Director, Support Groups

Amirah Limayo
 Senior Research Project
 Coordinator

Kelly Cox
 Director, Support Groups and
 Sr Dir, Regional Community Workshops

Danielle Doheny
 Director, Public Policy & Advocacy

Jason London
 Associate,
 Marketing, Communications, Web

Serdar Erdoğan
 Director, GMAN and European &
 Middle Eastern Patient Programs

Jim Needham
 Publication Design

Heather Fishman
 Donor Relations

Meghan O'Connor
 Coordinator, Meetings & Programs

Jon Fitzpatrick
 Technology and Coordination,
 Support Groups

Selma Plascencia
 Director, Operations

Sherrie Guerrero, SHRM-SCP
 Director, Human Resources

Annabel Reardon
 Senior Director,
 Strategic Program Management

Abigail Guzman
 Meeting Registration &
 Guest Relations

Joy Riznikove
 Database Analyst

Brenda Hawkes
 Director,
 Regional Community Workshops

Miko Santos
 Web Producer

Paul Hewitt
 InfoLine Coordinator

Kelley Sidorowicz
 Regional Director,
 Support Groups

Kevin Huynh
 Web Specialist

Sarah Solomon
 Donor Relations

Marya Kazakova
 Editor-in-Chief, Publications

Brando Sordoni
 Accounting & Distribution

Ilana Kenville
 Assistant Director,
 Member Events

Rafi Stephan
 Assistant to the President

Missy Klepetar
 InfoLine Coordinator

Robin Tuohy
 Vice President,
 Support Groups

Phil Lange
 Accountant

Judy Webb
 InfoLine Coordinator

Jonathan Weitz
 Donor Relations

Find information about the IMF Team at
imfteam.myeloma.org

¡USTED NO ESTÁ SOLO!



Las Voces de Mieloma – Grupo Virtual

Un grupo de apoyo voluntario para pacientes interesados, se anima a los cuidadores, familiares y amigos a unirse a nosotros. Se trata de una excelente manera de conocer e interactuar con otros supervivientes y cuidadores para conocer los últimos avances en el tratamiento y la gestión del mieloma.

Para más información:
lasvoces@imfsupport.org
lasvoces.support.myeloma.org



¡SABER ES PODER!



Non-Profit Organization
 US Postage
 PAID
 Permit #4330
 Los Angeles, CA

International Myeloma Foundation
 4400 Coldwater Canyon Avenue, Suite 300
 Studio City, CA 91604 USA

myeloma.org
 800.452.CURE

Change Service Requested

Printed in USA © 2022 International Myeloma Foundation. All rights reserved.

Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.



WHAT ACTION WILL YOU TAKE FOR MYELOMA ACTION MONTH?

March is Myeloma Action Month. The IMF invites YOU to TAKE ACTION because every action makes a difference! To foster community-building, please share your action with the hashtag **#MYelomaACTION** on social media and encourage others to join!

MAM.myeloma.org

LINK TO THE LATEST AT IMF **events.myeloma.org**

For information about international activities by IMF affiliates, please visit these websites:



Australia
myeloma.org.au



Canada
myelomacanada.ca



Israel
amen.org.il



Japan
myeloma.gr.jp



Latin America
mielomabrasil.org