COVER STORY

Yelak Biru
Leading the Way in the Fight Against Myeloma

The 26-year myeloma survivor and advocate has been named as the International Myeloma Foundation’s new President & CEO.
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Dear Friends,

Yet again, it is hard to believe that a full year has been consumed by the COVID-19 pandemic.

Despite the challenges, the International Myeloma Foundation has been hugely successful in reaching out to the myeloma community through unique educational and support programs, as well as myeloma expert collaborations and ongoing clinical and laboratory research.

We appreciate and thank most sincerely all who have contributed to the remarkable success and progress of the IMF amid a year of global setbacks.

Providing education and support to keep myeloma patients safe from COVID-19 has been the focus of the IMF’s many initiatives. A special COVID-19 page was created on the IMF’s website, blogs, and webinars highlighted key measures to stay safe, including getting vaccinated and boosted, using the right masks, and other necessary measures in situations of concern where there is an increased risk.

Many patients were able to take advantage of Zoom calls and webinar programs, with numbers ranging from several hundreds to a few thousands on some key updates. However, it is not possible to compare the impact of in-person meetings with virtual programs.

In addition, important myeloma research continued. The landmark ASCENT trial—where patients with high-risk smoldering myeloma (the earliest active disease with the best chance of achieving a cure) were treated with a decisive four-drug combination of best available drugs—completed accrual. We are awaiting longer-term results. The first patient for the trial achieved a fantastic response and is now MRD-negative after three years, with one year fully off any therapy. The initial trial results will be presented at the 2022 ASCO Annual Meeting.

Another great success was the Black Swan Research Initiative®-supported iStopMM® study. This study has over 80,000 participants from Iceland who have been screened to assess for the presence of early myeloma disease, such as MGUS or smoldering myeloma.

At the 2021 ASH Annual Meeting in Atlanta, six abstracts from the research were presented with four as oral presentations. Preliminary data suggest that this type of early screening will, indeed, lead to improved outcomes, including the detection of undiagnosed smoldering myeloma with the potential for decisive early intervention. In 2022, the results of the largest randomized myeloma trial ever conducted will become available. Early screening could become the new standard of care.

As always, our top priority is the well-being of myeloma patients everywhere. The IMF works every day to bring the myeloma community together to fight myeloma while keeping myeloma patients as safe as possible.

We have also developed programs that foster resilience to sustain our energies to get us through these difficult times.

Thanks to all our supporters for remaining with us in 2021, as they have in the past. For our part, the IMF will be resilient and unflagging in striving to achieve the best outcomes for all myeloma patients.

Sincerely yours,

Brian G.M. Durie, MD
Chairman, IMF Board of Directors

Dear Friends,

Another year has passed, and yet we are still in the midst of a pandemic.

Despite all the challenges, the International Myeloma Foundation has remained hopeful, resilient, and steadfast in its mission: to improve the quality of lives of myeloma patients while working toward prevention and a cure.

For more than 30 years, the IMF has been a catalyst for research, an accelerator of hope, and a partner to patients and their loved ones.

As a 26-year myeloma patient and long-time advocate for the prevention and cure of myeloma, I am humbled to join the organization as its new IMF President & CEO. I am grateful to be able to do what I am truly passionate about, in the service of those who love what we do.

I look forward to leading the very organization I turned to for guidance all these years and I sincerely thank the IMF for giving me this opportunity.

With your help and support, the IMF promises to continue to put myeloma patients at the center of everything we do—whether in research, education, support, or advocacy.

Our commitment to improving lives and finding a cure will never waver. We will always be here for you, and we are truly thankful to you for remaining by our side, especially during these challenging times.

Sincerely yours,

Yelak Biru
IMF President & CEO
On November 15, 2021, Yelak Biru was named President & CEO of the International Myeloma Foundation. Yelak became the President & CEO of the organization.

Born in Ethiopia, the 51-year-old Yelak earned undergraduate and graduate degrees in computer science from the University of North Texas. After graduating, Yelak worked in advanced business analytics at PepsiCo until 2017, then joined Walmart to work in global technology, focusing on talent management practices, strategic direction, and associate engagement.

At age 25, while studying at the University of North Texas, Yelak was diagnosed with multiple myeloma. Driven to learn more about the disease, Yelak became an active participant in local myeloma patient support groups and eventually became one of their prominent leaders—first in Texas, then in Arkansas.

Yelak has been a member of the IMF Board of Directors since 2015, and has participated in the National Institutes of Health (NIH) Council of National Institutes (NCI) Myeloma Steering Committee. He has also co-authored articles published in the Journal of the National Comprehensive Cancer Network and Blood Cancer Discovery and appears frequently at international medical conferences.

“Living with myeloma is not easy but having an organization like the IMF beside me during my cancer journey has helped me live with—and not for—myeloma.”

YE LAK B IR U

“In the development of so many new treatments over the past 20 years, patients can reimagine living with myeloma. That’s why it’s so important for an organization like the IMF to put patients at the center of the care process,” said Yelak. “With the development of so many new treatments over the past 20 years, patients can reimagine living with myeloma. That’s why it’s so important for an organization like the IMF to put patients at the center of the care process, education, support, and advocacy,” said Yelak. He looks forward to leading the IMF team to achieve the goals he set out to accomplish.

New IMF President & CEO Yelak Biru speaking at the 2018 GMAN Summit Plenary Sessions in Stockholm, Sweden. Yelak was named Chief Executive Officer by the International Myeloma Foundation on November 15, 2021, and subsequently, as IMF President & CEO.
UPDATE ON THE IMF’S BLACK SWAN RESEARCH INITIATIVE’S ISTOPMM PROJECT

The Black Swan Research Initiative® (BSRI) continues to make major strides with its ISTOPMM Project (Iceland Screens, Treats, or Prevents Multiple Myeloma). One of the largest studies ever conducted, the ISTOPMM Project has a record-setting 88,759 participants—the highest clinical participation ever for a single country.

The ISTOPMM study is the first of its kind to evaluate the benefits and harms of screening for patients with monoclonal gammopathy of undetermined significance (MGUS), a precursor to multiple myeloma in which an abnormal protein appears in the blood.

A Paradigm Shift in Myeloma Therapy

Oral Presentations from the ISTOPMM Study Take Center Stage at the 2021 ASH Annual Meeting

Four oral presentations containing data from the ISTOPMM Project were showcased at the 63rd American Society of Hematology (ASH) Annual Meeting, which was held in Atlanta, GA from December 11-14, 2021.

“These are the very first presentations to come out of the ISTOPMM study and it is extremely encouraging for us that they are so well received, highlighting [their] relevance and importance,” says Dr. Kristinsson.

The four ISTOPMM abstracts investigated:
• The impact of very early screening for MGUS and early intervention in smoldering multiple myeloma (SMM)
• The understanding of when to initiate treatment at the SMM stage
• The risk of COVID-19 in MGUS
• New testing that could lead to a more accurate diagnosis of monoclonal disease in those with kidney dysfunction

In a virtual biobank, all samples are collected, kept, and tested in a local setting with the results entered into a computer and submitted electronically for storage and analysis. This makes the process more efficient and attractive to investigators because they have control over their samples and can conduct testing that is of great interest to their patient population.

The Immune Therapy Registry

Through the efforts of investigators Dr. Thomas Martin (UCSF & Stanford), Dr. Ji Lin (Mayo Clinic—Rochester, MN), and Dr. Yi Lin (Mayo Clinic—Rochester, MN), the IMWG has engaged investigators, and pharma partners around the globe to gain a better understanding of how the different therapies work or what the best sequencing of drugs might be.

A NOTE ON THE IMF’S VIRTUAL BIOBANK AND IMMUNE THERAPY REGISTRY

The Virtual Biobank

The International Myeloma Working Group (IMWG) is currently developing a virtual biobank. Tissue samples (such as bone marrow and blood samples) are collected from patients undergoing treatment, particularly the newer immune therapy treatments, to better understand the mechanisms of why some patients respond while others do not.

The Immune Therapy Registry

The Immune Therapy Registry will be electronically housed at the University of California, San Francisco and will serve as a platform for investigators, and pharma partners around the globe to gain a better understanding of how the different therapies work or what the best sequencing of drugs might be.

OTHER KEY ISTOPMM PROJECTS IN 2021

The BSRI has over 50 ongoing projects worldwide. Here are some highlights:

• A BSRI team in Nantes, France, is studying the specificity of monoclonal protein. The preliminary results show that these proteins’ antibodies work against a range of infections, including Hepatitis C, H. pylori, and others. BSRI researchers are seeing what happens to the myeloma protein when you treat these infections.
• The Spanish team, Drs. Alberto Orfao, Bruno Paiva, Jesús San Miguel, and María V. Mateos have developed and refined minimal residual disease (MRD) testing using next-generation flow. Today, the team is using mass spectrometry to detect very low levels of myeloma protein. The team has learned that there is a subset of patients who are MRD negative and also negative with mass spectrometry, and also, another subset of patients who are MRD negative, but are MRD positive when detected by mass spectrometry. The BSRI team is working to follow up with these patients on a longer term to better understand low-level indolent disease versus those who are truly MRD negative.
• The BSRI is also doing retrospective studies. For example, the team is looking at the immunology and molecular features of long-term survivors (20 years or more).
• A next opportunity is to try to achieve MRD undetected at biochemical relapse. This BSRI concept has been introduced to patients with either persistent or recurrent MRD positivity.

SOME HIGHLIGHTS OF BSRI PUBLICATIONS FROM FISCAL YEAR 2021

Reference Values to Assess Hemodilution and Warn of Potential False-Negative Minimal Residual Disease Results in Myeloma


Iceland screens, treats, or prevents multiple myeloma (ISTOPMM): a population-based screening study for monoclonal gammopathy of undetermined significance and randomized controlled trial of follow-up strategies


Characterization of complete IncRNAs transcriptome reveals the functional and clinical impact of IncRNAs in multiple myeloma


B-Cell Regeneration Profile and Minimal Residual Disease Status in Bone Marrow of Treated Multiple Myeloma Patients


Monocyte Subsets and Serum Inflammatory and Bone-Associated Markers in Monoclonal Gammopathy of Undetermined Significance and Multiple Myeloma


Minimal residual disease negativity by next-generation flow cytometry is associated with improved organ response in AL amyloidosis


Characterization of rare germline variants in familial multiple myeloma


Deep MRD profiling defines outcome and unveils different modes of treatment resistance in standard- and high-risk myeloma

The IMF hosted the 12th Annual International Myeloma Working Group (IMWG) Summit virtually from June 22-23, 2021. Held online for the second year in a row, the Summit convened the world’s top myeloma experts. Its mission is to identify, support, and implement the most promising research to prevent the onset of active disease, to improve treatment, and to find a cure.

Dr. Shaji Kumar (Mayo Clinic—Rochester, MN) led the first session, a discussion of the 2/20/20 risk stratification model for high-risk smoldering multiple myeloma (HR SMM). This important advancement was developed as a result of an IMWG research project and published in Blood Cancer Journal in October 2020. Data was gathered from a large number of international sites to assess which patients with SMM had progressed, and which patients had not. The 2/20/20 system was devised in a collaboration between Dr. Kumar and Dr. Durie with the Spanish team led by Dr. Jesús San Miguel (Clínica Universidad de Navarra—Navarra, Spain) and Dr. María-Victoria Mateos (University of Salamanca—Salamanca, Spain).

The IMWG also developed a point scoring system and an online calculator app to identify ultra-high-risk SMM—a group for which immediate treatment can be strongly considered. Patients who score 12 or more points have ultra-high-risk SMM and are eligible for treatment.

Other highlights of the Summit included the presentation of the IMFs 20th Annual Robert A. Kyle Lifetime Achievement Award to Dr. Nikki Murshid, the Kraft Family Chair and Professor of Medicine at the Harvard Medical School and the Director of Basic and Correlative Science, and the Associate Director of the Jerome Liperi Myeloma Center at the Dana-Farber Cancer Institute in Boston, MA. This award honors an individual whose body of work has made significant contributions to myeloma research and patient care.

The Brian G.M. Durie Outstanding Achievement Award, recognizing excellence in myeloma research, was awarded to Dr. Shaji Kumar, a consultant in the Division of Hematology and the Mark and Judi Mullins Professor of Hematological Malignancies at Mayo Clinic in Rochester, MN. Dr. Kumar is also the Chair of the Myeloma, Amyloidosis, and Dysproteinemia Group, and an Associate Chair for research in the Department of Medicine at Mayo Clinic.

As is tradition with the Summit, the myeloma experts broke out into research in the Department of Medicine at Mayo Clinic. Mullins Professor of Hematological Malignancies at Mayo Clinic, Dr. Durie with the Spanish team led by Dr. Jesus San Miguel (Clinica Universidad de Navarra—Navarra, Spain) and Dr. Maria-Victoria Mateos (University of Salamanca—Salamanca, Spain).

The 4th Annual IMF Asian Myeloma Network (AMN) Summit was held from October 17–18, 2020. The event was originally scheduled to be in person in Singapore but became a virtual two-day gathering instead, due to COVID-19.

The AMN Summit is an annual gathering of leading myeloma specialists in Asia where the latest developments in myeloma diagnosis and treatment are shared, and discussions on priorities for action in the coming year are held in a workshop setting. Because in-person participation was not permissible, government regulations made accommodations to organize AMN "studios" in several major cities. Arrangements were made with the hub of the Summit in Bangkok and satellite studios were set up in Beijing, Seoul, Shanghai, and Singapore. This allowed AMN members to converge locally and to participate in the Summit.

AMN members and industry observers were also able to participate online from China, Hong Kong, Japan, Korea, Malaysia, Singapore, Taiwan, and Thailand.

In the U.S., Dr. Brian G.M. Durie (IMF Chairman of the Board) and his staff were able to join in from the IMF headquarters in Los Angeles. Myeloma experts Dr. S. Vincent Rajkumar (Mayo Clinic—Rochester, MN) and Thomas Martin (UCSF Helen Diller Family Comprehensive Cancer Center—San Francisco, CA) participated from other locations.

European myeloma experts Drs. Jean-Luc Harousseau (University of Nantes—Nantes, France), Alberto Orfao (University of Salamanca—Salamanca, Spain), and Stephen Harding (The Binding Site—Birmingham, West Midlands, UK) made contributions via recorded video. On Day 1, Frontline Therapy, Minimal Residual Disease (MRD), Immune Therapies, and Relapsed Myeloma were topics covered, with global perspectives presented by Dr. Rajkumar, Dr. Orfao, Dr. Martin, and Dr. Harousseau. Asian perspectives were presented by Dr. Wee Joo Chng (Singapore), Dr. Wening Chen and Dr. Juan Du (China), and Dr. Kihyun Kim (South Korea), respectively. Q&A panel discussions from AMN members followed the presentations.

Day 2 kicked off with reports made by the AMN Standing Committees on a virtual tissue bank (Dr. Chng and Dr. JH Lee of Korea); high-risk myeloma treatment (Dr. Chin of Hong Kong and Dr. Huang of Taiwan); the establishment of an AMN MRD sub-committee (Dr. Chunchanaree of Thailand and Dr. Chen); CAR T-cell clinical trials in Asia (Dr. Du and Dr. Martin); and Asian patient support (Dr. Tan of Singapore and Dr. Shimizu of Japan).

AMN members agreed to set up a virtual AMN Tissue Bank Project, to prepare clinical trial proposals for high-risk myeloma patients, to create an MRD program (including training for AMN centers), to pursue CAR T-cell and other immune therapy clinical trial projects, and to move ahead with a patient support program for each AMN country and region.

An update on ongoing AMN clinical trials and a discussion about future initiatives were also provided by Dr. Chng, followed by a review of algorithms for the treatment of myeloma. Dr. Rajkumar gave a global overview while Dr. Tan provided an Asian perspective.

Headed by Dr. Durie and Dr. Rajkumar, the final session of the AMN Summit focused on strategies for disease management and was especially lively, with guidance provided by the global IMWG experts.

**UPDATE ON AMN CLINICAL TRIALS**

The IMF carries out innovative clinical trials throughout Asia via the AMN’s Virtual Myeloma Network. Access data and access to novel therapies have become readily available to Asian myeloma patients because of these efforts.

- **AMN001** in 2019 was an access program with 136 relapsed myeloma patient participants who were previously exposed to bortezomib and lenalidomide and who were later treated...
Participants at the Asian Myeloma Network Summit

The International Myeloma Foundation (IMF) presented its 2021 Research Grant awards in December 2020 via a virtual ceremony with IMF Chairman of the Board Brian G.M. Durie, MD and IMF Founder Susie Durie.

Characterization of ROL-driven Lipogenic Signaling in Multiple Myeloma Cells

Cellular RNA can serve as a precursor for proteins or as an effector molecule with an active role in malignant transformation. We have discovered an RNA molecule (ROL) promoting the synthesis of lipids in multiple myeloma (MM) cells, these lipids can, in turn, be used as energy storage, for the synthesis of cellular membranes or to regulate the molecular signaling. We hypothesize that, by doing so, ROLs integrate with oncogenic proteins forming a novel discovered RNA-protein complex. The proposal is to investigate the molecular mechanism of ROLs to inform the development of clinically applicable novel therapeutic approaches for translation to clinical trials.

ABOUT EUGENIO MORELLI, MD

Dr. Morelli is a postdoctoral fellow at Dana Farber Cancer Institute and Harvard Medical School (Boston, MA, USA). He earned his MD in 2017 in the University of Cagliari (Sardinia, Italy), and completed a clinical/research fellowship in Medical Oncology at the same University. During his fellowship, Dr. Morelli gained expertise in molecular biology and experimental therapeutics of multiple myeloma. Under the mentorship of Dr. Pierfrancesco Tassone, he primarily focused on the biological role and therapeutic implications of small noncoding RNAs (i.e., microRNAs) in multiple myeloma, pioneering the use of primary microRNA (pri-miRNA) therapeutics of human cancer. Dr. Morelli joined Dr. Nikhil Munshi’s Lab at Dana Farber Cancer Institute in 2017 as a post-doctoral fellow. Since then, he has focused his research to systematically map functionally characteristic and therapeutically target long noncoding RNA (lncRNA) dependencies in multiple myeloma. His work has led to discover the novel IncRNA ROL regulator of lipogenesis (ROL), a critical role in driving the malignant phenotype of myeloma cells. The Brian D. Novis Junior Award will enable Dr. Morelli to decode the molecular mechanism and biologic role of ROL, in multiple myeloma, and to develop strategies to therapeutically target this IncRNA for translational to clinical trials. Dr. Morelli found the perfect environment in the Munshi Lab to pursue his scientific interests, and this Award will provide a significant boost to a rapid translation of his findings to the clinical setting to improve the outcome for myeloma patients.

The IMF’s Global Myeloma Action Network (GMAN) brings together advocacy leaders in multiple myeloma to improve the lives of myeloma patients around the world.

In fiscal year 2021, GMAN held a virtual meeting at the American Society of Hematology (ASH) Annual Meeting. In attendance were participants from countries and regions in Europe, Australia, Canada, Latin America, and the United States, as well as GMAN’s industry partners.

GMAN members gained knowledge about the latest advances in myeloma and engaged with disease experts. Of note were hybrid and virtual Patient Webinars that reported on best practices as well as Turkey’s pandemic project for myeloma patients.

In March 2021, GMAN members celebrated Myeloma Action Month (MAM) digitally through social media and online seminars. Online seminars and webinars were conducted for myeloma patients in Colombia, Hong Kong, Ireland, IMF, IMAN, Italy, South Korea, and Turkey with more than 6,000 attendees participating globally.

MAM graphs of “31 Days of Resilience” and “Myeloma Facts” were translated into several languages: Czech, French, German, Italian, Korean, Portuguese, Russian, Spanish, and Turkish.

The annual GMAN Summit was held virtually from August 25–26, 2021, with 50 advocates from 5 continents and 30 countries in attendance.

The panel discussion on “How Can We Improve Access to Trials for MM Patients?” was held with Dr. Brian Durie, Dr. Daryl Tan, Dr. Jean-Luc Harousseau, and Dr. Hartmut Goldschmidt in attendance. All agreed that identifying a “champion” is extremely important in smaller countries, if they are able to participate in trials.

One of the biggest highlights of the Summit was naming the recipients of the 2021 Susie Novis Durie Grant. This year the 2021 grants were announced for 4 countries: Austria’s “Home Training Exercise Program,” Croatia’s “Pathway to Clinical Trials in South Eastern Europe,” Israel’s “Raise Awareness Among Arabic Population,” and Portugal’s “Website Providing Professional Answers.”

The 2021 IMF Global Myeloma Action Network: Activities in Europe and Beyond
EMPOWERING PATIENTS

PATIENT EDUCATION

PRINT PUBLICATIONS
- ADDED 34 NEW EDITIONS IN THE IMF’S LIBRARY OF 100+ PUBLICATIONS

TRANSLATIONS
- SELECT IMF PUBLICATIONS AVAILABLE IN 19 INTERNATIONAL LANGUAGES
- TRANSLATED MYELOMA TODAY QUARTERLY INTO FRENCH, ITALIAN, GERMAN, & SPANISH

WEBNARS
- IMF’S POPULAR BROADCAST “LIVING WELL WITH MYELOMA”
  - 2,000 LIVE LISTENERS
  - 16,000 ARCHIVED RECORDING LISTENERS

NEWS PUBLICATIONS
- MORE THAN 40,000 readers of the MYELOMA MINUTE™ NEWSLETTER
- MORE THAN 75,000 readers of the MYELOMA TODAY™ JOURNAL

PATIENT OUTREACH

VIRTUAL SEMINARS
- HOSTED 14 WEBINARS THROUGHOUT EUROPE WITH MORE THAN 5,000 TOTAL ATTENDEES
- 2,000 LIVE ATTENDEES
- 10,000+ ARCHIVED LISTENERS

SUPPORT GROUPS
- HOSTED VIRTUAL SUPPORT GROUP LEADERS SUMMIT WITH 112 LEADERS ATTENDING WITH AN EXTENDED REACH OF 6,500+

FACILITATED 150+ TECH INSTRUCTION AND ONE-TO-ONE VIRTUAL MEETINGS

SOCIAL MEDIA
- CONNECTED WITH MORE THAN 126,000 FACEBOOK FOLLOWERS
- 3.1M REACHED
- 14,000 TWITTER FOLLOWERS
- 1.1M REACHED

INFOLINE
- THROUGHOUT THE COVID-19 PANDEMIC, THE INFOLINE TEAM HAS RESPONDED TO MORE THAN 6,000 CALLS AND EMAILS TO ADDRESS SPECIFIC NEEDS OF MYELOMA PATIENTS ACROSS THE GLOBE
- MORE THAN 6,500+ CALLS AND EMAILS
EMPOWERING PATIENTS

The IMF Nurse Leadership Board® (NLB) consists of nurse experts from leading medical centers who care for myeloma patients and who collaborate to improve their patients’ lives. Due to the pandemic, the NLB realigned many programs in 2021 by adapting in-person events to virtual programming.

The NLB’s 2021 Oncology Nursing Society (ONS) Satellite Symposium, "Case Studies in Myeloma Care for Challenging Times," took place online in April 2021. The distinguished NLB panel included NLB Chair Beth Faiman, PhD, RN, MSN, APRN-BC, AOCN®, FAAN; as well as NLB Faculty members Amy E. Pierre, RN, MSN, ANP-BC, Donna D. Catamero, ANP-BC, DNP, CCRC, and Charrise Gleason, MSN, NP-BC, AOCNP®. They presented six HPRA-compliant case studies, with each illustrating a myeloma patient at a specific stage of the disease.

This fiscal year, NLB members served as faculty at IMF education forums, including 4 Patient and Family Webinars, 10 IMF Regional Community Workshops, and 18 virtual support group presentations that reached over 14,000 participants. They also took part in the inaugural Power My Community Workshops to tackle awareness of multiple myeloma risks and disparities among the African American communities of Charlotte, Baltimore, and Atlanta.

Additionally, the NLB participated at the Support Group Leaders Summit, Support Group Leaders at ASM, and conducted numerous roundtables with both patients and professionals to fulfill their mission of improving care and quality of life for myeloma patients.

Last year, the nurses developed a popular treatment discussion tool. Eight hundred printed copies have been distributed so far. It is also available for download online along with a companion explanatory video which has been viewed 500 times. This year, the NLB nurses are tackling a new tool for patients to facilitate difficult conversations about myeloma with their loved ones.

The NLB revealed their new patient education deck, "Life Is A Canvas, You Are the Artist," at the 2021 August Patient and Family Webinar. They participated in IMF educational video vignettes for patients which address newer treatment options and mechanisms of action, and they are making finishing touches on the first round of the Myeloma University video series which will be made available in 2022.

Finally, travel restrictions could not deter the important work of the NLB. At the 17th annual meeting that was held virtually in September, the NLB discussed addressing disparities, particularly regarding clinical trial enrollment. They also updated their educational case studies and worked on developing tools for both patients and nurses to provide valuable insights into treatment options among the relapsed/refractory patient population.

The COVID-19 pandemic also created much-needed public awareness about the vast health disparities in our nation. President Biden and Members of Congress recognized this issue and began to seriously discuss taking steps to address it. The IMF, in collaboration with various coalitions, has been working to advance bills addressing health disparities, particularly in clinical trials.

The IMF has also acted as active coalition members, who advocate for an increase in research funding. Particular efforts are being placed on the National Institutes of Health (NIH), the National Cancer Institute (NCI), the Department of Defense’s Congressionally Directed Medical Research Program (CDMRP), and the U.S. Food & Drug Administration (FDA) to help continue scientific progress and to bring new therapies to patients more quickly.

The IMF has long supported the inclusion of “blood cancers” as a topic area in the Congressionally Directed Medical Research Program (CDMRP) Peer-Reviewed Cancer Research Program (PRCRP). This inclusion is important because it allows myeloma researchers to apply for grant funding through this program and the IMF to nominate myeloma patients to participate and engage in the program as consumer reviewers. These efforts require us to approach Congressional leaders and make the case for blood cancers.

Congress has been talking steadily about toxic exposures veterans have faced. Congressional leaders in both the House and the Senate have made it clear that they intend to address toxic exposure issues this Congressional term. They have been focusing steadily on building the support of the Blue Water Navy Vietnam Veterans Act, a bill endorsed by the IMF. Many bills have already been introduced to help veterans who have been faced with toxic exposures. Hearings have been held surrounding this important matter.

The IMF recognizes that veterans facing a myeloma diagnosis often have unique experiences and differing access issues compared to other patients. In 2021, the IMF’s Veterans Against Myeloma (VAM) program continued to focus on ensuring that policymakers are made aware of the needs of veterans to make sure that myeloma remains as a service-connected disease.

The IMF has been actively working to address the needs of those who do not benefit from state bills. On July 9, 2021, H.R. 4385 was reintroduced to the House of Representatives. This bill has bipartisan support and would help many of the individuals not reached by state-level laws already passed. Due to political issues, the bill had to be restructured slightly 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. The IMF has made it an even larger priority to advance the bill and has been strategizing, working with Congressional stakeholders, and aggressively pushing legislative efforts.

One issue that remains particularly important, especially in light of the ongoing pandemic, is the issue of accessibility of oral anticancer medications. Oral parity legislation addresses this issue by ensuring that oral chemotherapy drugs, like many of the drugs taken by myeloma patients, are covered by insurers in the same way as IV therapies. The IMF previously worked to pass laws to ensure this equitability at the state level. Due to these efforts, 43 states along with Washington, D.C. have state-level laws addressing this issue. That said, federal legislation is still needed.

The IMF has been actively working to address the needs of those who do not benefit from state bills. On July 9, 2021, H.R. 4385 was reintroduced to the House of Representatives. This bill has bipartisan support and would help many of the individuals not reached by state-level laws already passed. Due to political issues, the bill had to be restructured slightly 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. The IMF has made it an even larger priority to advance the bill and has been strategizing, working with Congressional stakeholders, and aggressively pushing legislative efforts.

The IMF has been closely monitoring Congressional efforts to address toxic exposure issues. As these conversations progress, we will make sure that legislators will have the needs of veterans with myeloma represented.
MEMBER FUNraisers

COOKING FOR A CURE / MAY 23, 2021
Participants learned cooking skills from Chef Alonso Roche and prepared a meal together for them to enjoy following the cooking lesson.

LAUGHS 4 LIFE / JULY 30, 2021
This night of comedy featured Nate Bargatze and Leanne Morgan, and generated smiles and laughter throughout the wonderful Hub City community in Hattiesburg, MS.

HATFIELD HIKE / SUMMER 2021
Bill Hatfield, with his dog, Huckleberry, hiked the Appalachian Trail this past summer to raise awareness and donations for the IMF and another charity.

#KNOWMYELOMA VARIETY SHOW / SEPTEMBER 30, 2021
This Twitch.TV livestream featured performers who have been affected in one way or another by myeloma, including internationally touring comedian Forrest Shaw, “Ologies” podcast host Alie Ward, Dance Theatre of Harlem ballerina Daphne Lee, LA-based writer and mom Jen Curran, and IMF Chief Medical Officer Dr. Joseph Mikhael.

DONOR SPOTLIGHT

KRISTI WILLETT:
‘FIGHT THE FIGHT AND NEVER GIVE UP!’

Kristi Willette has had a long-term relationship with the International Myeloma Foundation—spanning more than twenty years. It all began after her husband, Chick Willette, was diagnosed with myeloma in November 1999. The Willettes were referred by Chick’s attending physician, Dr. Louis Vandermolen of Hoag Hospital in Newport Beach, to IMF Chairman of the Board Dr. Brian G.M. Durie for a deeper assessment and for in-depth knowledge about the disease. Dr. Vandermolen and Dr. Durie worked closely together in developing a treatment plan for Chick, allowing him to live for 13 years.

However, the Willettes’ relationship with the IMF would go beyond myeloma treatment and care. Kristi fondly recounted how, in subsequent years, she and her husband would cross paths with Dr. Durie and Susie Novis Durie at the Annual Comedy Celebration and how gracious the Duries had always been to her and Chick.

For several years, Chick was in remission but in 2009, Chick had a relapse. They were again referred to Dr. Durie to consult for a possible new treatment or a trial study. One trial was enough for Kristi to be hopeful but instead, Dr. Durie provided them with five treatment options—recommending one in particular. Chick’s doctor administered the treatment plan recommended by Dr. Durie and Chick was able to live for three more years, traveling with his wife and enjoying life.

When Chick passed away in August 2012, he provided for a foundation in his trust. “In the years leading up to his diagnosis, we had talked about giving back in one form or another. Upon Chick’s passing, a not-for-profit trust was created. One area of focus would be cancer research leading to a cure for multiple myeloma,” Kristi recounted.

A year later, the Willette Charitable Foundation was established—inspired by Chick’s dignity, grace, and great fight against myeloma, and by the “genius and talent” of the medical professionals that the Willettes had gotten to know over the years. The Willette Charitable Foundation made its first donation to the IMF in December 2013.

“Our mission statement is to promote and support cancer research, treatment, care, and financial assistance,” said Kristi.

The Willette’s remarkable relationship with the IMF has made Kristi especially interested in supporting the IMF’s endeavors—particularly in the field of research and the Black Swan Research Initiative.

“The Black Swan Research Initiative was so exciting when announced, as the word ‘cure’ was never in the same sentence as multiple myeloma. We supported some truly wonderful research to put the IMF on the path to this enormous goal,” Kristi recalled.

When the StopMM® trial was presented, we split our efforts as it seemed to be a very viable avenue of research. When would this opportunity presented by Iceland ever exist again? Having an entire country involved in the search for a cure is the ideal setting! The country has a medical database for all citizens. The isolation of country and very limited cross-culturalization presents the perfect setting,” Kristi further added.

When asked about her interest in the IMF’s advocacy, webinars, new treatments, and International Myeloma Working Group’s (IMWG) guidelines, Kristi had this to say: “I have always been impressed with the work and reporting of the IMWG. I have been privileged to be an onlooker at these meetings. These are my favorites of the ASH annual conference. Sitting on the sidelines and hearing a global effort to find the cure. Listening to the challenges each country faces and working together to overcome so many challenges can only be the road to success.”

“The IMF is unique in that they have reached out to all corners to share information, share a focused goal to eradicate this terrible disease. They have worked diligently with government agencies, pharmaceutical companies, scientists, investigators, donors, and corporate foundations to drive their mission. Their efforts continue to amaze me. I know their heart and their being is all about this pursuit: TO FIND A CURE!” Kristi enthused.

In closing, Kristi shared some encouraging words for the myeloma community: “Never give up. The strides toward this goal have provided better ways to live with myeloma while the research is boldly in full swing. Finding the key to unlock the door to a cure is the IMF’s waking mission. Never give up on taking full advantage of all the IMF offers: education through Dr. Durie’s blogs, the continued reporting of advancements, and telephone support.”

“*The IMF is there for you at every step. You only need to reach out. Fight the fight. Appreciate your caregivers. The IMF gives full support not only to their patients but to all those who support you in the fight against myeloma. You never have to feel you are alone. The IMF is there for you,” Kristi assured.*
WAYS TO GIVE

ONE-TIME GIFTS:
All amounts help—from $5 to $500. Visit donate.myeloma.org NOW!

TRANSFORMATIONAL GIFTS:
Honor a loved one with a tribute gift, recognize a physician or nurse, support IMF research with a major gift. These gifts are integral to the success of the IMF. Contact Lynn Green, IMF Senior Vice President, Philanthropy, at lgreen@myeloma.org or 818-487-7455 x268.

MONTHLY GIFTS:
Join the IMF’s Hope Society by making monthly gifts. Starting at $10 per month, you can support IMF core programs, including educational events, publications, the toll-free InfoLine, and more! New members can select a limited-edition Hope Society gift. Contact Jonathan Weitz, IMF Donor Relations, at 1-800-452-2873 ext. 254 or jweitz@myeloma.org to learn more.

PLANNED GIFTS:
Support the IMF and plan for your future through various planned giving options such as bequests and IRA contributions. These gifts are an excellent way to receive additional tax benefits. Contact Lynn Green, IMF Senior Vice President, Philanthropy, at lgreen@myeloma.org or 818-487-7455 x268.

LEGACY GIFTS:
Support the IMF’s mission of prevention and finding a cure for multiple myeloma through a gift in your will. The IMF has partnered with our friends at FreeWill (https://www.myeloma.org/freewill) to allow you to write a free, legal will online in less than 25 minutes. Save time and money while securing your legacy for the people and causes you love today.

STOCK GIFTS:
Donations of stock or other securities offer ideal opportunities to receive additional tax benefits through your philanthropic giving. Should you or your financial advisor have additional questions, please contact Lynn Green, IMF Senior Vice President, Philanthropy, at lgreen@myeloma.org or 818-487-7455 x268.

INTERNATIONAL MYELOMA FOUNDATION
Statement of Financial Position
September 30, 2021

ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current assets</td>
<td>$4,933,768</td>
</tr>
<tr>
<td>Investments, at fair value</td>
<td>$12,575,957</td>
</tr>
<tr>
<td>Contributions, program grants, and other receivables</td>
<td>$1,156,224</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>$515,429</td>
</tr>
<tr>
<td>Total current assets</td>
<td>$19,613,378</td>
</tr>
<tr>
<td>Other assets</td>
<td>$357,956</td>
</tr>
<tr>
<td>Total assets</td>
<td>$19,971,334</td>
</tr>
</tbody>
</table>

LIABILITIES AND NET ASSETS

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Liabilities</td>
<td>$1,160,541</td>
</tr>
<tr>
<td>Deferred program and educational grants</td>
<td>$4,065,524</td>
</tr>
<tr>
<td>Refundable advances</td>
<td>$2,253,000</td>
</tr>
<tr>
<td>Gift annuity obligation</td>
<td>$71,500</td>
</tr>
<tr>
<td>Total liabilities</td>
<td>$7,552,565</td>
</tr>
<tr>
<td>Net Assets</td>
<td>$11,743,790</td>
</tr>
<tr>
<td>With donor restrictions</td>
<td>$244,979</td>
</tr>
<tr>
<td>Total net assets</td>
<td>$11,986,769</td>
</tr>
<tr>
<td>Total liabilities and net assets</td>
<td>$19,539,334</td>
</tr>
</tbody>
</table>

For a copy of our complete audited financial statements, please contact the IMF office.
INTERNATIONAL MYELOMA FOUNDATION

Statement of Activities and Changes in Net Assets for the Year Ended September 30, 2021

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>REVENUES AND SUPPORT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational and program grants</td>
<td>$ 7,428,870</td>
<td>$ 2,430,000</td>
</tr>
<tr>
<td>General contributions</td>
<td>2,641,247</td>
<td>329,046</td>
</tr>
<tr>
<td>Clinical trials and research revenue</td>
<td>4,262,599</td>
<td>-</td>
</tr>
<tr>
<td>Change in split interest agreements</td>
<td>-</td>
<td>(4,574)</td>
</tr>
<tr>
<td>Support group income</td>
<td>29,815</td>
<td>-</td>
</tr>
<tr>
<td>Fundraising events, net of direct benefit to donors of $168,323</td>
<td>-</td>
<td>154,235</td>
</tr>
<tr>
<td>Investment income, net of fees $59,412</td>
<td>634,659</td>
<td>16,162</td>
</tr>
<tr>
<td>Transfer to annuity assets</td>
<td>(7,812)</td>
<td>7,812</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>2,762,280</td>
<td>(2,762,280)</td>
</tr>
<tr>
<td>TOTAL REVENUES AND SUPPORT</td>
<td>$ 17,752,658</td>
<td>$ 169,401</td>
</tr>
</tbody>
</table>

FUNCTIONAL EXPENSES

Program expenses | 13,512,687 | - | 13,512,687 |
General supporting expenses | 655,289 | - | 655,289 |
Fundraising | 1,115,813 | - | 1,115,813 |

TOTAL FUNCTIONAL EXPENSES | $ 15,283,789 | - | $ 15,283,789 |

CHANGE IN NET ASSETS

2,468,869 | 169,401 | 2,638,270 |

NET ASSETS - Beginning of year | 9,272,921 | 75,578 | 9,348,499 |

NET ASSETS - End of year | $11,741,790 | $244,979 | $11,986,769 |

INTERNATIONAL MYELOMA FOUNDATION

Statement of Functional Expenses for the Year Ended September 30, 2021

Breakdown of Expenses by Program

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>TOTAL EXPENSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research</td>
<td>$7,268,622</td>
</tr>
<tr>
<td>Education and Awareness</td>
<td>1,855,781</td>
</tr>
<tr>
<td>Support Groups</td>
<td>815,003</td>
</tr>
<tr>
<td>Patient and Family Seminars</td>
<td>573,017</td>
</tr>
<tr>
<td>Advocacy</td>
<td>568,222</td>
</tr>
<tr>
<td>International</td>
<td>536,180</td>
</tr>
<tr>
<td>Nurse</td>
<td>473,063</td>
</tr>
<tr>
<td>Website</td>
<td>453,728</td>
</tr>
<tr>
<td>InfoLine</td>
<td>446,723</td>
</tr>
<tr>
<td>Myeloma Today</td>
<td>309,343</td>
</tr>
<tr>
<td>Clinical Meetings</td>
<td>149,179</td>
</tr>
<tr>
<td>Information Mailings</td>
<td>63,826</td>
</tr>
</tbody>
</table>

Total Program Expenses | $13,512,687 |
Fundraising Expenses | 1,115,813 |
General Supporting Expenses | 655,289 |

Total Expenses | $15,283,789 |

Revenue Breakdown

- Research 42%
- General Contributions 15%
- Education & Other Program Grants 16%
- All Other 4%

Expense Breakdown

- Program Expenses 39%
- Fundraising 7%
- General Support Expenses 4%
- Research 4%