



**ANNUAL
REPORT
2021**



Our Vision

A World without Waldenstrom's macroglobulinemia (WM).

Our Mission

Support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) while advancing the search for a cure.

Our Values

Community

We believe in engaging the WM community by sharing information, providing support, and working together to eradicate the disease.

Integrity

We care about the WM community and commit to the highest financial and ethical standards, with transparency in all that we do.

Teamwork

We work as a team that includes all WM stakeholders.

Focus

We are fiercely dedicated to providing support and education for those affected by WM and supporting research to improve and extend lives and find a cure for the disease.

Collaboration

We leverage the collective passion and genius of other blood cancer organizations and the medical and research communities.

Accountability

We are transparent and accountable at every level to the WM community and the general public.



IWMF LEADERSHIP MESSAGE



PETER DENARDIS

IWMF Chair of the Board



NEWTON GUERIN

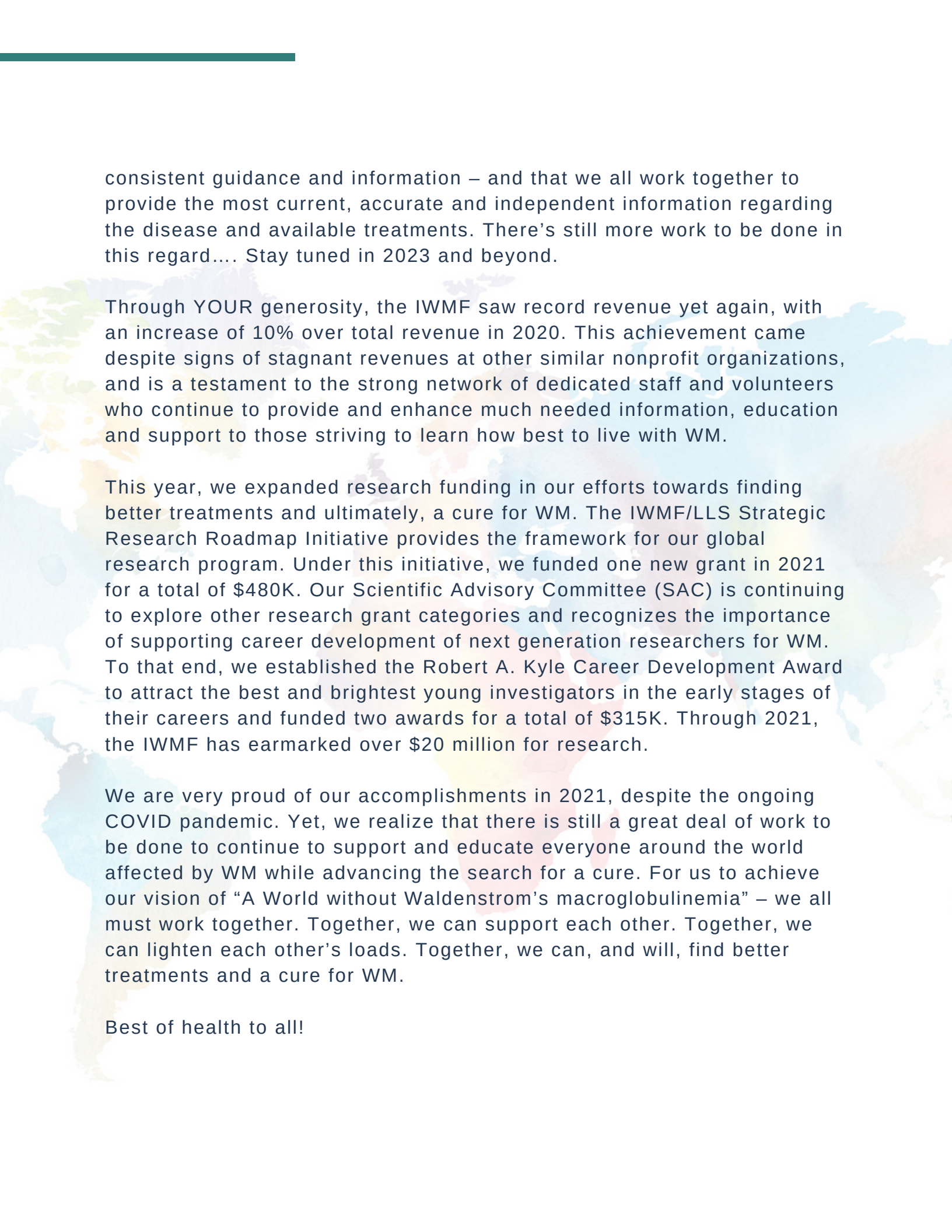
IWMF President & CEO

Dear Friends of the IWMF,

In 2021, the global WM community continued to face the prospect of having to contend with an ongoing COVID-19 pandemic. Fortunately, for the general public, the opportunity for vaccines and treatments in 2021 helped mitigate concerns about the severity of the disease. Yet, the immunocompromised status of WM patients continued to make living in a COVID-19 world a challenging prospect for them and their families.

Despite the challenge of the continued practice of social distancing among the WM community, the staff and volunteers at the IWMF found novel ways to continue to provide education and support around the world utilizing a variety of online platforms. Specialized support sessions were created and made available for previously underserved groups including “Young People Living with WM”, “People of Color Living with WM”, “Bing Neel”, and “Peripheral Neuropathy”. These groups of WM patients, caregivers, family members, and friends took advantage of the opportunity to meet virtually with folks around the world who shared similar focused concerns and issues. In fact, were it not for the COVID pandemic, these opportunities may not have happened!

The IWMF also embarked on a “Global Patient Initiative”, initially working with major cancer patient organizations in the United States, to provide a forum for us to work together to ensure that, no matter where a patient goes for the latest information regarding WM, they obtain the same



consistent guidance and information – and that we all work together to provide the most current, accurate and independent information regarding the disease and available treatments. There's still more work to be done in this regard.... Stay tuned in 2023 and beyond.

Through YOUR generosity, the IWMF saw record revenue yet again, with an increase of 10% over total revenue in 2020. This achievement came despite signs of stagnant revenues at other similar nonprofit organizations, and is a testament to the strong network of dedicated staff and volunteers who continue to provide and enhance much needed information, education and support to those striving to learn how best to live with WM.

This year, we expanded research funding in our efforts towards finding better treatments and ultimately, a cure for WM. The IWMF/LLS Strategic Research Roadmap Initiative provides the framework for our global research program. Under this initiative, we funded one new grant in 2021 for a total of \$480K. Our Scientific Advisory Committee (SAC) is continuing to explore other research grant categories and recognizes the importance of supporting career development of next generation researchers for WM. To that end, we established the Robert A. Kyle Career Development Award to attract the best and brightest young investigators in the early stages of their careers and funded two awards for a total of \$315K. Through 2021, the IWMF has earmarked over \$20 million for research.

We are very proud of our accomplishments in 2021, despite the ongoing COVID pandemic. Yet, we realize that there is still a great deal of work to be done to continue to support and educate everyone around the world affected by WM while advancing the search for a cure. For us to achieve our vision of “A World without Waldenstrom’s macroglobulinemia” – we all must work together. Together, we can support each other. Together, we can lighten each other’s loads. Together, we can, and will, find better treatments and a cure for WM.

Best of health to all!



LOIS HELLRIEGEL: A WM STORY

My WM story:

I'm originally from Buffalo, NY area. Winters were brutal with Lake Effect snow but, summers were delightful! I truly enjoyed summer at my parent's cottage on the Canadian north shore of Lake Erie. Being a summer born baby, my first home was Canada.

Most of my life was spent in Western NY and Southern Ontario. Ultimately, I married a Canadian and applied for residency followed by citizenship, dual citizenship. I continued to work in Buffalo in adult education, social work, and counseling.

Travel has always brought me joy. As my husband's health declined, we purchased a small RV to escape the winter weather. This made traveling with medical paraphernalia more manageable.

After my husband passed away, I realized I needed a course in RV for Dummies. It was that or sell. Owning an RV is a lot like owning a house with plumbing, sewage, electrical systems, inverters, and converters. I found a course offered by the RV manufacturer in Manitoba, Canada. It seemed reasonable to go where they knew my machine and specific systems. Then, off I went on my first solo trip.

With my new empowerment, I entered another life phase... On the road!

I played it safe the first year by exploring Florida. The mission in the Keys was to find the best Key Lime Pie. I was up to the challenge. Then came 2 winters in Mexico where the highlights included the Copper Canyon, forests of overwintering Monarch butterflies, and diving with Manta Rays. Perhaps, best of all was rescuing a little street dog from Cabo. His name, Tope', refers to a Mexican speed bump. My little speed bump taught me many life lessons on survival and gratitude.



As time passed, I found my energy waning. On my next trip to Florida, although it was not my intent I ended up with condo in Fort Myers. The view took my breath away.

Then came another phase, WM.

A lot of stuff was going on with me physically for much of my life with no answers. Autoimmune labels came and went. Eventually, I gave up looking for answers.

On an adventure travel excursion something went horribly wrong. After months of physical therapy, I was referred to yet another specialist. He found the ensuing problem and much more - something unrelated. An MRI revealed bone marrow issues. Two years later, after numerous frustrating medical encounters, a WM diagnosis.

Surprisingly, the revelation was not so overwhelming. One of the greatest frustrations is knowing something isn't right and having no affirmation. On some level, it was almost reassuring to have a definitive diagnosis. My initial reaction was mostly confusion over the term "Watch and Wait". Ultimately, after a deep dive into my new and rare disease, I digested the W&W concept and welcomed some distance from additional toxins.

When the need for treatment did come, I was somewhat well prepared. My research provided me with a WM specialist and educated me on clinical trials. I entered a clinical trial and found a therapy was right for me.

IWMF has become my new best friend. I immersed myself in the educational videos. The Connect platform brought me up to date on important considerations and I gained insight into critical issues and decision making. Now with ongoing Covid restrictions, yoga offerings provide me with healthy alternatives and a personal support community.

Thank you IWMF.

IWMF giving message

Years ago, my financial advisers told me how much joy I should be experiencing in my estate planning. They stressed that connecting with charitable organizations and directing the planning would be rewarding and satisfying.



My initial thought was of pure drudgery followed by avoidance and resistance. My conflicting emotions finally settled on - just get it done!

Many years after my initial hesitancy and on-the-fly versions of estate planning, a Waldenstrom's diagnosis entered my life. Those chaotic early days of web searching ultimately led me to the IWMMF. What a gift of a find. The educational resources and physicians' references started me on a new path.

A quote from Robin Roberts kept resounding in my mind. "Make your mess, your message." I still hear her voice today. Through my mess, I found a true mission. This past year I have truly enjoyed fine tuning my charitable giving. I have worked with various IWMMF staff along with my financial and legal advisors. Together we developed a plan that does indeed make me smile. It reflects my passion and values.

Staff members gently guided me through the process by providing critical information as to how we could make a plan that would truly express my desires. Up to this point, my directives merely designated a percentage to research and a percentage to client services. Newton Guerin IWMMF's Chief Executive Officer kindly laid out the various research funding options which included Research Roadmap grants and the Robert A. Kyle Career Development Award grants. On the mission program side, options included Support Group Leaders training and an area referred to as Living, Learning, and Thriving with WM focused programs. He helped break all this down so that my project was manageable. I have been able to distribute my giving to the various grants as best fits my mission. Finally, I could see how my funding will make a difference.

I explored endowment funding and decided it was not for me. My choice was to make a bigger impact sooner rather than slowly over time. **I'm all for finding a cure sooner than later!**

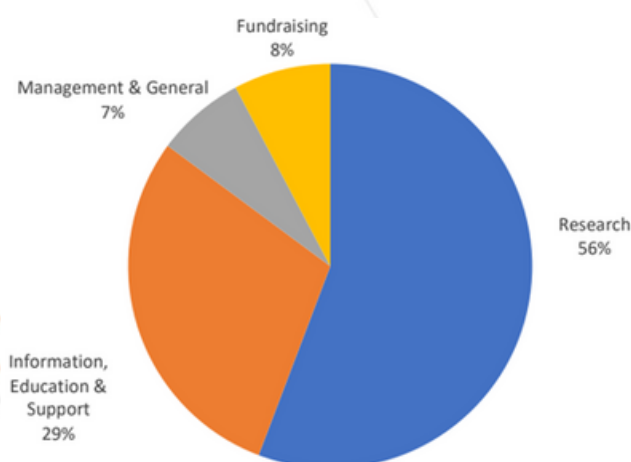
I now spend my time between PA and FL with Jazz the Maltese an IWMMF ambassador who sports his IWMMF bandana raising awareness wherever we go.

YOUR SUPPORT IS INVESTED WISELY

In fiscal year 2021, IWMF raised \$4.46 million to support our mission and operations. We spent \$2.09 million or 85% of our expenses on specific programs designed to find new treatments for WM and improve the lives of patients and their families.

The IWMF has achieved a Charity Navigator overall score of 95.47 on a scale of 100, and a 100 rating on accountability and transparency.

In 2019, the IWMF's received its fourth consecutive 4-star rating from Charity Navigator. 2020 and 2021 have not yet been rated. Only 21% of the organizations reviewed by Charity Navigator have received this ranking four years in a row. This outside confirmation of what the IWMF has done should be a strong signal that donating to the IWMF is a good investment.



Consolidated Statement of Activities for the year ended December 31, 2021 (US dollars)

Revenue:	
Campaign Contributions	4,454,466
Other Income	2,598
Net interest and dividend Income	4,096
Total Revenue:	4,461,160
Expenses:	
Research	1,365,815
Information, Education & Support	724,343
Total Program Services	2,090,158
Management and General	174,415
Fundraising	190,625
Total Expenses:	2,455,198
Change in Net Assets	2,005,962

Consolidated Balance Sheet As of December 31, 2021

Assets:	
Cash and cash equivalents	6,167,020
Prepaid Expenses and other assets	150,481
Contributions and other receivables, net	1,007,613
Fixed Assets, net	76,925
Total Assets:	7,402,039
*Liabilities:	
Accounts payable & accrued Expenses	141,984
Deferred revenue	13,333
Other long term liabilities	0
Total Liabilities	155,317
Net assets:	
Without donor restriction	1,761,886
With donor restriction	3,478,874
Net Income	2,005,962
Total Net Assets	7,246,722
Total Liabilities and Net Assets	7,402,039

*The IWMF Board of Directors have approved multi-year agreements for research grants totaling \$1,771,509. These grant payments are conditional and are not included as liabilities on this consolidated balance sheet.

BEN RUDE HERITAGE SOCIETY

The Ben Rude Heritage Society (BRHS) recognizes those who have made provisions for a future gift to the IWMF, such as a bequest, listing the IWMF as a beneficiary for a life insurance policy or qualified planned asset (such as a 401k or IRA), or a life income agreement, such as a Charitable Remainder Trust. Legacy gifts represent an important component of the IWMF's financial future. There are many ways to support the IWMF through a planned gift, but a bequest is perhaps the easiest and most tangible way to leave a lasting impact. The following supporters are members of the Ben Rude Heritage Society:

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RESEARCH PARTNERS

For a commitment of \$50,000 per year for a minimum of two years, or a lump sum of \$100,000 or more, you can become a research partner supporting a specific IWMF research project approved by the IWMF's Scientific Advisory and Research Committees. Research Partners will have an opportunity to be kept informed of the progress of the research project and will be formally acknowledged by the investigators in their report of the project as well as in any resulting publications. Generally 10 to 12 research projects are underway with new projects under consideration each year. The following funds support current IWMF research:

**The David and Janet Bingham
Research Fund of the IWMF**

**The Elting Family
Research Fund of the IWMF**

**The Lynn M. Fischer
Research Fund of the IWMF**

**The Robert Douglas Hawkins
Research Fund of the IWMF**

**The K. Edward Jacobi
Research Fund of the IWMF**

**The Michael and Rosalie Larson
Research Fund of the IWMF**

Leukaemia Foundation of Australia

**The Carolyn Morris
Research Fund of the IWMF**

**The Ed and Toni Saboe
Research Fund of the IWMF**

**The Paul and Ronnie Siegel Family
Research Fund of the IWMF**

Waldenstrom's Macroglobulinemia Foundation of Canada

**The Robert and Nadeline White Family
Research Fund of the IWMF**

**The Marcia Wierda
Memorial Fund of the IWMF**

**The Yang Family
Research Fund of the IWMF**

NAMED GIFT FUNDS

For a commitment of \$10,000 per year for five years, or a lump sum of \$50,000 or more, you can establish a named fund at the IWMF in your own name or in the name of someone you wish to honor. The following funds support information, education, mission programs, research, or a combination of each:

Baker Family
Research Fund of the IWMF

Yoshiko Button
Mission Support Fund of the IWMF

Friedlander-Scherer Family
Research Fund of the IWMF

Helene Ettelson
Research Fund of the IWMF

Gary Green
Research Fund of the IWMF

Dr. Robert A. Kyle and Charlene M. Kyle
IWMF Career Development
Research Fund

Lynn Martin and Carrie Wells
Research Fund of the IWMF

Dennis and Gail Mathisen
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Gail Murdough
Mission Support and Research Fund of the IWMF

Sesnowitz Family
Research Fund of the IWMF

Donald and Alison Weiss and Family
Research Fund of the IWMF

Donald and Kathryn Wolgemuth
Research Fund of the IWMF

Joseph and Maureen L. Janda
Research Fund of the IWMF

If you have discretionary giving power and would like to help move our research program forward in a special way, we invite you to join those listed above. For more information about Research Partners and Named Gift Fund opportunities and potential gifting options that might make that possible, please contact Director of Development and Communications Alix Redmonde at ARedmonde@iwmf.com or 941-927-4963.

OUR SUPPORTERS

The work of the IWMF would not be possible without the generosity and support of people like you. On behalf of the entire WM community, we offer our sincerest thanks for your support in 2021:

\$1,000,000+

John Button

\$500,000 - \$999,999

Elizabeth Elting

Ron Holten

Rosalie Larsen

\$100,000 - \$499,999

BeiGene, Ltd.

Parmie M. Byrd

Janssen Oncology

Leukemia & Lymphoma Society (LLS)

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\$50,000 - \$99,999

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Johnson & Johnson Health Care Systems, Inc.

Maynard Morris

Edward and Toni Saboe

The Patterson Foundation

Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC)

Kenneth Wierda

\$25,000 - \$49,999

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Col. USAF Ret. David and Penny B. Kirby Jr.

Leukaemia Foundation - South Australia

John D. and Catherine T. MacArthur Foundation

Richard B. Siegel Foundation

X4 Pharmaceuticals

\$10,000 - \$24,999

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American Endowment Foundation
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