# International Waldenstrom's Macroglobulinemia Foundation

2022 Annual Report



# International Waldenstrom's Macroglobulinemia Foundation

Website: iwmf.com Email: info@iwmf.com Phone: 941-927-4963 • International: 001-941-927-4963



The IWMF, the only international organization dedicated solely to Waldenstrom's macroglobulinemia, is a patient-founded and patient-driven nonprofit with a simple but compelling vision and mission.

VISION: A world without Waldenstrom's macroglobulinemia.

**MISSION:** Support and educate everyone affected by Waldenstrom's macroglobulinemia to improve patient outcomes while advancing the search for a cure.

The IWMF is committed to creating a world without WM by finding a cure. Since 1999, the IWMF has invested over \$23 million in WM research projects throughout the world. Thanks to this research, WM patients are living longer and have better treatment options that can lead to longer-lasting remissions with fewer side effects.

## Visit the IWMF website to:

- Download a free Newly Diagnosed Info Pak.
- Learn about WM and download free publications available in multiple languages.
- Find curated resources to help support your mental, physical, and financial health.
- Join a local IWMF Support Group or IWMF International Affiliate.
- Refer to the IWMF Directory of Physicians available for consultations or second opinions.
- Subscribe to the IWMF Torch, our free quarterly newsletter.
- Participate in the annual IWMF Educational Forum or our online webinars.
- Join IWMF Connect, an online community offering a wide variety of moderated WM-related email discussions, or the IWMF Facebook Discussion Group.
- Find contact information for our partner organizations.

The IWMF relies on donor contributions to fulfill its mission, and we welcome your support. You can contribute to the organization by visiting our website or by mailing a check to:

International Waldenstrom's Macroglobulinemia Foundation 6144 Clark Center Avenue Sarasota, FL 34238

The IWMF is a 501(c)(3) tax-exempt nonprofit organization, Fed ID #54-1784426

### 2022 Annual Report



Dear Friends of the IWMF,

Top of mind for many of us during 2022 was the transition that occurred around the globe from a COVID pandemic status to an endemic one. Vaccines and boosters became more readily available and mandates were lifted. As we all moved forward throughout the year, we focused on adhering to the vaccination and masking protocols suggested to us by our medical teams – and the IWMF continued to encourage everyone to follow their doctors' guidance in this regard.

For patients and caregivers, however, managing the process of improving our quality of life while facing Waldenstrom's macroglobulinemia still remained the top priority from a personal health perspective. In fact, that top priority is one shared by the IWMF, which is led by a Board of Trustees comprised of patients and caregivers.

On an annual basis, the IWMF Board of Trustees revisits the organization's strategic plan to ensure that it continues to focus on the appropriate priorities for everyone around the world dealing with WM. During its November 2022 Meeting, the Board modified our mission statement to ensure a focus on improved quality of life by adding "to improve patient outcomes" to the message.

#### **IWMF MISSION**

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

The Board also took action to modify the key strategic goals that help the IWMF Board, Staff, and volunteers remain focused on improving the lives of patients and caregivers. These strategies (formerly named "Compelling Intentions") also took on more of a global focus to help us better meet the needs of everyone,



**PETER DENARDIS** IWMF Chair of the Board



**NEWTON GUERIN** IWMF President & CEO

regardless of where they live. As a result, those strategies were renamed "Global Imperatives."

### Global Imperatives (formerly "Compelling Intentions")

- **1. Research:** Expand leadership role to significantly increase the number, scope, and coordination of global WM research projects.
- 2. Patient Support:
  - Awareness: Ensure everyone affected by WM knows about the resources we offer.
  - Education & Support: Be the authoritative source for patient and caregiver education and support.
- **3. Healthcare Professionals Awareness:** Reach more patients sooner by ensuring every healthcare professional working in blood cancer is aware of the IWMF and its resources.
- **4. Partnership:** Actively pursue and develop relationships with like-minded organizations to accomplish our mission.
- 5. Fundraising: Significantly increase and diversify our sources of funding.

From a **"Patient Support"** perspective, the IWMF began to re-introduce in-person program options (where prudent), and further enhanced virtual meeting opportunities. Technology used for virtual sessions enabled us to better meet the needs of previously underserved segments of our community, such as "Young People Living with WM," "People of Color Living with WM," "Bing Neel," and "Peripheral Neuropathy." Through key online programs, we enabled folks to continue to meet virtually. As a result, more people than ever are now able to participate in the IWMF's information, education, and support programs. From **"Patient Support," "Healthcare Professionals** Awareness" and **"Partnership"** perspectives, we grew collaborations that made it possible to adapt and disseminate accurate, and up-to-date information to the global WM community. The IWMF-led "Global Patient Initiative" partnered with other lymphoma patient organizations to provide a forum to work

Much of the WM research currently being conducted simply would NOT happen were it not for the IWMF (and the generosity of our donors)! You can read more about our latest grants and the amazing work that researchers around the world are doing on your behalf at: https://iwmf.com/current-research-recipients/.

From a **"Fundraising"** perspective, the IWMF recognizes that we could not have grown our information, education, support and research programs without the generosity of IWMF's donor community around the world. While the two simple words, "Thank You" can be used to convey our gratitude, it truly is difficult to arrive at sufficient phrasing to convey the extent of our gratitude for enabling us to continue to work towards our mission of improving patient outcomes while advancing the search for a cure.

Because of the generosity of the IWMF's incredible donor community, our overall financial position is now stronger than ever. This has enabled our team of dedicated volunteers and staff to continue to expand the IWMF's information, education and support programs for those striving to learn how best to live with WM. Yet, there is still much work to be done, as we continue our efforts to connect with patients and caregivers throughout the world, and researchers continue their effort to develop better, less toxic, and longer lasting treatments for WM.

We are extremely proud of the IWMF's impact on the lives of people living with Waldenstrom's macroglobulinemia. For the IWMF to achieve our vision of "A World without Waldenstrom's macroglobulinemia" – we all must work together. We welcome your advice and guidance along the way. Please feel free to reach out to us whenever you want. You can find contact information for our staff, officers, and Board of Trustees in the "About IWMF" link on the IWMF website.

Best of health to all!

addition, we partnered with Scientific Education Support, a UK-based medical education provider, to create a WM section of Lymphomahub.com, a highly regarded online resource for healthcare providers throughout the world. From a **"Research"** perspective, in recent years we have witnessed substantial progress in basic biomedical research and subsequent clinical management of

together to ensure that, no matter where a patient

looks for the latest information regarding WM, they

find the same consistent guidance and information.

This will now include expanding WM education and

awareness among healthcare providers. To the end,

we began work on a first ever professional education

booklet, Waldenstrom's Macroglobulinemia Essen-

tial Information: Physicians Guide, and a comparable

resource for nurses, Waldenstrom's Macroglobulin-

emia Essential Information: Nurses Guide, along with

a companion booklet for patients, Waldenstrom's

Macroglobulinemia Essential Information: A Patient's

Guide, each of which will be published in 2023. In

ical research and subsequent clinical management of Waldenstrom's macroglobulinemia. We were pleased to fund research grants in three categories:

**IWMF-LLS STRATEGIC RESEARCH ROADMAP** 

**INITIATIVE** - These grants continue our commitment to search for a cure and identifies the five focus areas in basic biomedical research where we are seeking research project proposals. This year the IWMF has added companion projects to the initiative for basic science projects within a clinical trial. The IWMF has supported many important WM research initiatives in the past and is well positioned to provide sustained funding to meritorious research proposals in the future.

**ROBERT A. KYLE CAREER DEVELOPMENT AWARD** - IWMF's Scientific Advisory Committee (SAC) recognizes that it is vital to provide funding to support the career development of next-generation researchers for WM. Our goal with these awards is to attract the best and brightest young investigators to WM research in the early stages of their careers.



# The Faces of WM



# **Betty Ann Morton** Downers Grove, Illinois

When I was diagnosed with Waldenstrom's macroglobulinemia back in 2001, I thought I was going to die,

quite possibly within the year. My diagnosis was unexpected because I thought my health was good. After all the tests, I was diagnosed by my mother, not my oncologist (who thought it was multiple myeloma.) Mom said, "You know, your grandmother had some strange anemia. Let me find out what it was." The oncologist agreed that I had it too. Bizarre to recall, but the diagnosis was a relief. The reality was so much better than my fears.

Once I connected with the IWMF and a local support group, I began to learn more about WM and what to look for on my blood test results. Over the last 22 years I've had several successful treatments, and fortunately very few of my days are limited by health problems. With the support of the IWMF, my fears have decreased, and my knowledge has increased. Through the IWMF's annual Educational Forums, written materials, and Wellness programming, I feel more confident in dealing with my WM. Thanks to the WM community and the IWMF, life is good, and giving back as a volunteer keeps me busy! I write for the IWMF Torch newsletter, provide support for others in the WM Facebook Support group, and regularly donate to the IWMF financially. Our contributions enable the IWMF to continue its awesome work of providing support and information to patients (like me!) and their families, as well as funding research into new and better treatments, with a goal of finding a cure.



# **Gordon Blackwell** Richmond, VA

I was diagnosed with WM in July of 2021. At the start, I was confused and unfamiliar with this rare cancer, and

through internet research I found the IWMF's website. I started regularly attending the yoga, exercise and meditation classes offered by the IWMF's Wellness Program. Through these classes, I also discovered a community of other WM friends who provided a place of safety and understanding that no one else in the world could. They have become my extended family, giving me hope and reassurance when I couldn't find it anywhere else.

The IWMF has been a life-changing resource for me. With medical treatment, the stress management techniques I learned through the IWMF's integrative offerings, and the support of my new community - I'm on the road to recovery. My wish is that everyone who receives the diagnosis of WM consider joining the WM Wellness community; or donating so that our Wellness Program can continue to grow and thrive. I might have an incurable cancer, but thanks to my new wellness approach, I can live with it!

# **İWMF**

# **The Faces of WM**



## **Patricia James** Powder Springs, GA

I am a 71-year-old African American woman with a diagnosis I spent a lot of time learning to pronounce

- Waldenstrom's macroglobulinemia. Not only could I not pronounce it; I could not explain it to my friends and family. It took 1.5 years and five different medical specialists to determine what was happening to my body and get a diagnosis. Initially, I was told I had multiple myeloma; this was not good news at all (not that Waldenstrom's was any better.) The final determination was made in 1992 at age forty, and we were at a loss on where to go from this point. For the next twenty years, I would not meet anyone with this disease or who had heard of it. It was also rare among African Americans. I finally learned of the work of the International Waldenstrom's Macroglobulinemia Foundation (IWMF). This was amazingly good news!

Through IWMF, I have gained a cohort of medical professionals and staff who are devoted to educating the masses about this complicated disease. I am grateful for the WM People of Color group established to bring people such as myself together. Thank you IWMF, for all you do to ensure the world is continually made aware of the nuances of Waldenstrom's. Your contributions to healthcare, and the resources you provide are much needed and are a significant factor in the longevity of patients. I applaud the continued effort of this organization and will continue to support the IWMF via participation with various conferences and fundraising efforts.



# Ken Goldner Plymouth, MA

My journey with Waldenstrom's began when I started experiencing symptoms of peripheral neuropathy (PN.)

After many tests, and finally a bone marrow biopsy, I was diagnosed. So, in a way, the PN was a blessing because it uncovered the WM. Still, it really scared me when I heard the word "cancer," and I began to wonder "how long do I have?"

My answer came soon enough. I was reading an article about WM in the Boston Globe's magazine section by Lisa Wise, one of the IWMF's longtime officers, and I said "WOW, there is an organization dealing with WM?" I quickly found the IWMF website, and learned through various resources that this diagnosis was not necessarily a death sentence, and that plenty of people were living longer and longer with WM. The probable cause of my WM was exposure to Agent Orange during the years I served in the Air Force.

Through reading the IWMF Torch newsletter and hearing other people's stories, I felt reassured that I wasn't alone. And although the PN has affected my mobility considerably, thanks to my wife who never lets me give up, I started attending the IWMF's online yoga classes. The classes keep me moving and even help with my neuropathy. I'm happy to give back to the IWMF by talking to anyone with WM, especially military – and I donate to the IWMF and encourage everyone to do the same. Even though we are bombarded by various fundraisers, we still need to support IWMF because WM is such a rare diagnosis.



# **The Faces of WM**



# Marty Vanderlaan San Francisco, CA

I have the unusual experience of having worked on the development of Rituxan while I was a Genentech

employee, and then receiving the very same Rituxan as my treatment for Waldenstrom's Macroglobulinemia. My role in the clinical pipeline was to develop product testing to ensure quality control. Since retiring, I have returned to Genentech to give talks as "the voice of the patient," with an emphasis on the importance of product quality. It was therefore inspiring to attend the recent 2023 IWMF Educational Forum in St. Louis and realize how many attendees had been and continue to be helped by Rituxan.

My own journey with WM started with a lung deposit of Amyloid AL, for which I received an Autologous Stem Cell Transplant. WM is not gone, but my wife and I recently celebrated the six-year anniversary of my transplant. Getting involved with the IWMF has been an important part of my journey: I both volunteer as a Lifeline volunteer for Amyloidosis and serve as a grant reviewer on the IWMF Research Committee. As a rare disease, WM does not attract much research funding from government sources like the National Institutes of Health, so progress in finding a cure depends heavily on donations to the IWMF. These donations also help fund the annual IWMF Ed Forum, which is a great way to meet other WM-ers and stay up to date on the latest treatments so that we can live longer, better lives.



## **Jason Euzukonis** Boxford, MA

My WM journey started in 2018 when I was 44 years old, which is a good twenty years younger than the average age of diagnosis. I was very

sick and weak from the anemia when I was first diagnosed, and like many others with cancer, I struggled with a massive amount of fear and anxiety. Fortunately, the advancements in new treatment options made in recent years allowed me to get back to full health quickly. I was also able to find the Eastern MA support group and the Young WM support group through the IWMF. These groups have been instrumental in helping me to get past my anxiety and allowing me to maintain good mental health.

Five years have passed, and I've become more involved with the IWMF by attending the Ed Forum and taking on a more active role with the support groups with the goal of passing on what I've learned to help others in their WM journey. I have no doubt that the research and advancements that have given me a chance to raise my two young children and live a full life would not be possible without the IWMF – but none of this happens without the generosity of those who can contribute financially to the IWMF. All of us benefit as a result!

# **WMF**

# Your Support is Invested Wisely

This fiscal year 2022, IWMF has raised **\$4.17 million** to support our mission and operations.

We have spent **\$2.1 million** or **82.6%** of our expenses on specific programs designed to find new treatments for WM and improve the lives of patients and their families.

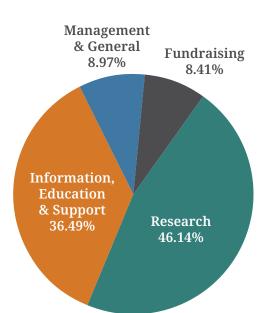
### Consolidated Statement of Activities as of 12/31/22 (US dollars)

### **Revenue:**

Campaign Contributions Other Income Net interest and dividend Income	\$4,133,881 (\$459) \$36,032
*Total Revenue:	\$4,169,454
Expenses:	
Research	\$1,179,213
Information, Education & Support	\$932,592
Total Program Services	\$2,111,805
Management and General Fundraising	\$229,257 \$214,856
Total Expenses:	\$2,555,918
Change in Net Assets	\$1,613,536

\* Currently the BRHS has identified potential gifts totaling \$10,777,785. Since these contributions can be rescinded at any time they are not recorded as revenue.

\*\* The IWMF has committed to future research grant projects under contract in the amount of \$1,666,635. Additionally the IWMF has approved future research project NOT yet under contract in the amount of \$600,000.



#### Consolidated Balance Sheet as of 12/31/22

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Revenue:	
Cash and cash equivalents	\$6,983,378
Prepaid Expenses and other assets	\$184,324
Contributions and other receivables, net	\$1,768,900
Fixed Assets, net	\$72,360
Other Assets	\$81,930
*Total Assets:	\$9,090,892
Liabilities:	
Accounts payable & accrued Expenses	\$175,069
Deferred revenue	\$0
Other long term liabilities	\$55,564
** Total Liabilities	\$230,633
Net assets:	
Without donor restriction	\$3,627,574
With donor/time restriction	\$3,619,149
Net Income	\$1,613,536
Total Net Assets	\$8,860,259
Total Liabilities and Net Assets	\$9,090,892

# **Ben Rude Heritage Society**

The Ben Rude Heritage Society 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 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 reports 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 David Hamberg Family** 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 K. Morris** Research Fund of the IWMF

**The Poh Family** 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 Research 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 gift fund at the IWMF in your own name or in the name of someone you wish to honor. The following funds support information, education, support programs, research, or a combination:

**Baker Family** Research Fund of the IWMF

**David and Lois Baru and Family** Research Fund of the IWMF

**Yoshiko Button** Mission Support Fund of the IWMF

Helene Ettelson Waldenstrom's Macroglobulinemia Research Fund

Friedlander-Scherer Family Research Fund of the IWMF

**Gary Green** Research Fund of the IWMF

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## **Gail Murdough**

Mission Support and Research Fund of the IWMF

**The Rosen Family Foundation** 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

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, Donor Engagement, Annette Preston at apreston@iwmf.com or 317-919-8238.

WM is a rare disease, but with the IWMF you are never alone.

# **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 2022:

## \$1,000,000+

John Button

## \$500,000 - \$999,999

Liz Elting

## \$100,000 - \$499,999

BeiGene USA, Inc. Cellectar Biosciences, Inc. James Kelly Leukemia & Lymphoma Society (LLS) Paul & Ronnie Siegel

## \$50,000 - \$99,999

Johnson & Johnson Health Care Systems, Inc. Maynard Morris Pharmacyclics Sian Poh Andy Ruland Ed & Toni Saboe Susan Sherwin Waldenstrom's Macroglobulinemia Foundation of Canada (WMFC) Kenneth Wierda

## \$25,000 - \$49,999

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# **İWMF**

## \$5,000 - \$9,999

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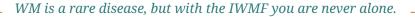
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