



International Waldenström's  
Macroglobulinemia Foundation

ANNUAL  
REPORT  
2020



### **Our Vision**

A World without WM (Waldenstrom's macroglobulinemia).

### **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.





# CARL HARRINGTON: A LOOK BACK

Dear friends of the IWMF,

The global COVID-19 pandemic made 2020 an incredibly challenging and frightening year for Waldenstrom's Macroglobulinemia (WM) patients and their families. However, due to the hard work, perseverance, ingenuity, and generosity of our staff, our volunteers, the IWMF Board, and the entire WM community, we moved closer to our goal of a "World without WM." Notable accomplishments in 2020 included:

**Record revenue of over \$4,000,000**, up 39% vs. 2019.

For perspective, total health care giving in the US was down 2% in 2020 vs. 2019, while medical research giving was down 11.9% per the Blackbaud Institute. A heart-felt thank you to all our donors for your very generous support!

**Expanding research** support by establishing the Dr. Robert Kyle Career Development Award to support promising young researchers in WM. Since 1999, the IWMF has funded over \$20,000,000 in WM-specific research, which has led to better treatments with fewer side effects and a very significant increase in life expectancy for WMers. Since 2015, research has been driven by the IWMF-LLS Strategic Research Roadmap, which evaluates and funds the best research projects on a global basis.

**Pivoting to online support** to ensure that people with WM everywhere had easy access to the information and support they needed about our rare disease. On short notice, our staff moved the in-person Educational Forum planned for Seattle, WA to an easy-to-use online site. Attendance soared from our usual 350-400 in-person attendees to over 1,400 registrants from over 30 countries. The overall rating for the Educational Forum was 4.71 out of 5, equivalent to a grade of 94, proving the willingness of our largely older community to learn new tricks and, ensure they are never alone.



All of our global support groups switched to online Zoom groups. Again, attendance increased as we were able to reach people who couldn't travel or didn't live near an existing support group. And we also established a series of online training sessions to help our support group leaders do their very challenging jobs.

**Expanding our global network** by adding new affiliates in Israel, South Africa, Portugal, and Chile and adding new WM expert clinicians in Argentina, China, Greece, Israel, Poland, Russia, and South Africa. All our publications continue to be published in at least seven languages.

**Improving our educational materials** through a new, easier-to-use website launched in November. We also created five global educational webinars that reached over 3,000 people with WM worldwide.

**Shifting the IWMF Board to a strategic board** from an operating board. Consistent with the strategic plan adopted in 2019, the IWMF hired Newton Guerin as President and CEO in February 2020. Newton's years of experience with the American Liver Foundation, Leukemia & Lymphoma Society, National Multiple Sclerosis Society, the American Cancer Society, and the International Dyslexia Association have provided tremendous value and greatly aided this critical transformation. Peter DeNardis, a long-time IWMF Board member, became chair of the IWMF Board of Trustees in December 2020, and four new Board members were added in the second half of 2020 to help the Board achieve its new goals.

While we are proud of what we were able to accomplish in 2020 despite the pandemic, we are not satisfied, and we never will be until we reach our goal of a "World without WM." With your continued financial support and emotional support for each other, we will keep expanding and improving. Remember: **With the IWMF, you are never alone.**

Carl Harrington  
Chair, IWMF Board of Trustees (2012 - 2020)





# EVERETT ELTING: A WM STORY

Ten years ago at the age of 75, I needed a knee replacement, the result of many years of hard court tennis. When the pathologist did a perfunctory biopsy on the offending knee after it had been removed just to insure that the surgeon had not done unnecessary surgery, a disease was discovered in the knee. Logic said that if the knee was diseased, so must be the body. The original diagnosis was lymphoma, and that was later refined to WM.

While I have kept pretty current about treatment options, I have been fortunate to not have any serious symptoms, so I have not considered any treatment options at this time. **Thanks to the resources available through the IWMF, I'll be ready when the time comes.**

I usually hesitate before I give too much advice to other people whether they are family, friends, or people that I don't know. But I'll tell you what I think: **Waldenstrom's is not a death sentence**. A large number of those afflicted will live long enough to die of something else rather than WM. It is, for many, a situation that we merely need to be aware of, and for others an affliction that needs to be managed. For some, there are life modifications that need to be made, although I am one who has not needed to do that. Fortunately, there are very worthwhile treatment options that can be utilized when necessary. Outstanding research is being conducted, and eventually there will be a cure; In the meantime there will be better and better treatment available. Optimism is important when it comes to Waldenstrom's, as it is in most aspects of life.

Waldenstrom's has changed me and my life in one important way: I get more out of every day than ever before. I have been diagnosed with Waldenstrom's, a serious and potentially fatal disease. As a result, I have a realization that I need to redouble my efforts to get more out of every day, to enjoy every moment, and to tell those that I care about how much they mean to me.

**After ten years since my original diagnosis, I have lived some of the best years of my life, and, to a great extent, I have Waldenstrom's to thank for that.**

My wife, Joanne, and I are very active. We play golf three times a week, and I look forward to doing that for as long as possible. We love to travel. I look forward to getting back to exploring the world. I love time spent with my kids and grandkids, and when their busy schedules permit, I get great joy from that. I have always been involved with some charitable endeavors. I do not want to be so presumptuous as to tell others what to do, but, for me, I would say enjoying life to the fullest is a good prescription for happiness. WM has given me an added incentive for that.







# ELIZABETH ELTING: A DAUGHTER'S STORY

My dad was diagnosed with Waldenstrom's macroglobulinemia in 2011.


It's going to be a familiar story to anyone reading this, no doubt, united as we all are by our experience with loved ones suffering from this illness, or by our own affliction. We only found out because he was hospitalized for something entirely unrelated.

My father has always been athletic and a sports lover; he was an avid tennis player throughout most of his life. But the human body can only take so much, and every single step, however considered, was a blow to his knees. By 2011, the damage was so great that his tennis days were over, and he needed a complete knee replacement. But once his surgeons got in there, they discovered something terribly wrong with his blood. It took something as dramatic as wrecking his knee to discover the indolent illness spreading throughout his blood by degrees.

With his diagnosis of Waldenstrom's came a five-year prognosis, and we prepared for the worst. I'm forever thankful that the worst never came, and he's long since outlived his initial prognosis—**a feat that that many have achieved thanks to the incredible strides in research made possible by the IWMMF. Just as much as the research the IWMMF supports, I'm grateful for the support I've found here, and the support I've in turn been able to offer.**

If there's anything I've learned from my dad over the course of my life, it's perspective. From childhood lessons on independence, self-reliance, and positivity to his lifelong commitment to fitness and health, to his chin-up response to his diagnosis, he's always had an attitude that, while easily mistaken for "always look on the bright side of life," is much richer than that. It's an attitude of what I'll call "optimistic resignation." **Your fate, in short, is what you make of the circumstances you're given. Wealthy or poor, healthy or sick, your life is ultimately your own.**





At the end of the day, we are the captains of our fate; we live and we die by our own decisions, and the mark we leave on the world is ours to choose. It's why I, after learning of the IWMF in early 2017 (a full six years after my father's diagnosis, and a year after his life was supposed to be over) began donating \$500,000 a year to its work, and why I continue to do so. The money given through the Elizabeth Elting Foundation, and through our family, is a fraction of what my father has given me in my life. It was the upbringing my father offered that made my success possible. I'm proud to be able to support the IWMF's work, **The goal isn't just philanthropy as an abstract good; it's to participate meaningfully in something that affects not only my father, but countless others.**

What I hope to do, more than anything, is to help people see that WM isn't a death sentence. That has been the greatest lesson my dad has taught me these last few years. You can look at it as a sword dangling over your head or as a daily reminder to live your life on your own terms. By supporting research that helps doctors identify and treat WM, we—you and I, together—can make those years as meaningful as possible, allowing those with WM to live their lives on their own terms. **Remember that we only get one go-round in this world and to spend it living, loving, and doing good. The IWMF makes it possible for so many to live their own lives, not under the sword of WM, but in the liberating light of life.**



# PETER DENARDIS: A LOOK AHEAD

Dear friends of the IWMF,

In December 2020, I assumed the role of Chair of the IWMF Board of Trustees. This position has a long history of volunteer patients who have each, in their own way, successfully propelled the IWMF further in its mission to “support and education everyone affected by Waldenstrom’s macroglobulinemia (WM) while advancing the search for a cure.”

Naturally, first and foremost, my objective is to do justice to those who came before me, and to do my best to follow in their footsteps.

Looking ahead, the IWMF will continue to sharpen its focus on education and research by pursuing such innovative strategies as:

**Create a global collaboration for WM with other international cancer organizations.** The intent is to ensure that, no matter where one happens to end up when searching for digital information about WM, the IWMF will have already developed and provided the background material for that information. As a result, everyone wins – patients and caregivers are provided with the most accurate, up-to-date details regarding diagnosis of, treatment for, and living with WM.

**Focus on providing opportunities for young investigators new to the field of WM** so that they can expand their knowledge and understanding of our disease and, in turn, become WM experts who can propel the next generation of treatments for us.

**Provide mentorship/fellowship opportunities to clinicians and researchers** so that they can become more conversant about WM and establish stronger relationships with current WM experts around the world.





**Further expand medical research** activities around the world by providing opportunities and incentives to researchers to work in the WM disease space.

**Enhance educational content** for the global WM community, ensuring that the information is updated based on the latest research findings and treatment recommendations, and capitalizing on the newest mechanisms available for disseminating that information.

**Engage with the global WM community** by seeking out new ways to interact and by taking advantage of social media tools and technology.

**Elevate the visibility of the IWMMF** so that any person around the world that is newly diagnosed will automatically get connected with the informational, educational, and support services we provide.

**Reach out to currently underserved communities** of WM patients and caregivers by expanding the IWMMF affiliate and support group network (if you're interested in setting up an affiliate and/or support group in your geographic area, please contact the IWMMF home office).

The IWMMF is a patient/caregiver-led organization, with a relatively small staff of highly talented and committed individuals. Still, we can't accomplish all our objectives nor provide the most comprehensive services and support to the global community of WM patients and caregivers without financial support from that community, and from pharmaceutical sponsors. Towards the objectives of further expanding WM-specific research activities, and of taking educational and support services to the next level, we are embarking on an ambitious fundraising effort over the next five years. Stay tuned for some exciting new giving opportunities where everyone can participate (no matter how large or small the donation) and engage with people with WM around the world.

Best of health to all!

Peter DeNardis  
Chair, IWMMF Board of Trustees (2020 - Present)

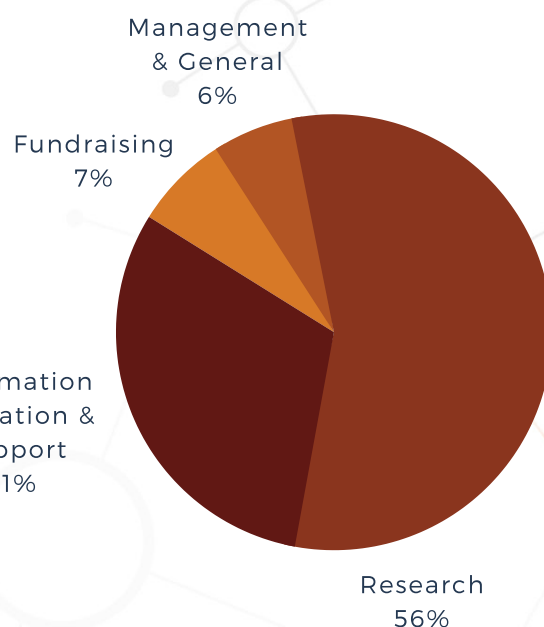


# YOUR SUPPORT IS INVESTED WISELY

**In fiscal year 2020, IWMMF raised \$4.080 million to support our mission and operations.** We spent \$2.263 million or 87.15% of our expenses on specific programs designed to find new treatments for WM and improve the lives of patients and their families.

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

This is the IWMMF's fourth consecutive 4-star rating from Charity Navigator. Only 21% of the organizations reviewed by Charity Navigator have received this ranking four years in a row. This outside confirmation of what the IWMMF has done should be a strong signal that donating to the IWMMF is a good investment.



## Consolidated Statement of Activities for the year ended December 31, 2020 (US dollars)

### Revenue:

Campaign Contributions	\$	3,989,770
Other Income	\$	82,850
Net interest and dividend Income	\$	7,809
<b>Total Revenue:</b>	<b>\$</b>	<b>4,080,429</b>

### Expenses:

Research Grants	\$	1,457,166
Information, Education & Support	\$	805,623
<b>Total Program Services</b>	<b>\$</b>	<b>2,262,789</b>

Management and General	\$	163,279
Fundraising	\$	170,306
<b>Total Expenses:</b>	<b>\$</b>	<b>2,596,374</b>

<b>Change in Net Assets</b>	<b>\$</b>	<b>1,484,055</b>
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## Consolidated Balance Sheet as of December 31, 2020

### Assets:

Cash and cash equivalents	\$	4,606,674
Prepaid Expenses and other assets	\$	73,220
Contributions and other receivables, net	\$	547,508
Fixed Assets, net	\$	90,530
<b>Total Assets:</b>	<b>\$</b>	<b>5,317,932</b>

### Liabilities:

Accounts payable & accrued Expenses	\$	77,171
<b>Total liabilities**</b>	<b>\$</b>	<b>77,171</b>

### Net assets:

Without donor restriction	\$	2,410,402
With donor restriction	\$	2,830,359
<b>Total net assets</b>	<b>\$</b>	<b>5,240,761</b>
<b>total liabilities and net assets</b>	<b>\$</b>	<b>5,317,932</b>

\*\*The IWMMF Board of Directors have approved multi-year agreements for research grants totaling \$1,950,815. 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 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:

ANONYMOUS (4)  
JEAN-MARC AUDIBERT\*  
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C. EDWIN BAKER\*  
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\* Deceased

♦ Founding Member

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

**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**

**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**

**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**  
**Research Fund of the IWMF**

**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 Jeremy Dictor at [JDictor@iwmf.com](mailto:JDictor@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 2020:

**\$1,000,000+**

The Lynn M. Fischer Research Fund of the IWMF

**\$500,000 - \$999,999**

Elizabeth Elting

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

BeiGene, Ltd.  
Catherine Howell and Michael D. Ernst  
Janssen Oncology  
Pharmacyclics

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

Maynard Morris  
Howard Prass  
Edward and Toni Saboe  
The Patterson Foundation  
Robert White  
Kenneth Wierda

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

Gina Maya and Richard Capelouto  
Stanley Kaufman  
Leukaemia Foundation - South Australia  
Waldenstrom's Macroglobulinemia Foundation of Canada  
Ralph Zuckerman

**\$10,000 - \$24,999**

Annette and Elias Aburdene  
Frederick and Almie Baker  
Dr. H. David and Lois Baru  
John Ciesielka and Dale Bottoms  
Dorothy Bryan  
Anita and Bruce Buyer  
Collectar Biosciences, Inc.  
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**\$1,000 - \$4,999**

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Teresa and Wayne Holimon  
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William and Kristine Howanski  
John and Lee Howard

**\$1,000 - \$4,999**

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