International Waldenstrom's Macroglobulinemia Foundation

2023 Annual Report

IWMF

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International Waldenstrom's Macroglobulinemia Foundation (IWMF), the only international organization dedicated solely to Waldenstrom's macroglobulinemia (WM), 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.

IWMF is committed to creating a world without WM by finding a cure. Since 2000, IWMF has invested more than 30 million USD 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 magazine.
- Participate in the annual IWMF Educational Forum and our online webinars.
- Join IWMF Connect, an online community offering a wide variety of moderated WM-related email discussions and the WM Support Group on Facebook.
- Find contact information for our partner organizations.

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 the following address:

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

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

IWMF Leadership Message

PETER DENARDIS
IWMF Chair of the Board

NEWTON GUERIN
IWMF President & CEO

Dear Friends of IWMF,

As we look back on the past year, we are humbled and grateful to share our 2023 Annual Report highlighting our collective efforts, achievements, and unwavering commitment to our mission to support and educate everyone affected by Waldenstrom's macroglobulinemia (WM) to improve patient outcomes while advancing the search for a cure.

As a mission-driven, non-profit organization, we recognize that innovation plays a key role in addressing challenges and creating positive change. Embracing new ideas enhances our overall effectiveness and ensures that "with IWMF, you are never alone." To continue to better meet the needs of the global WM community, it is critical that IWMF creates a culture that promotes continuous improvement and fully embraces fostering growth and innovation in everything we do. Listening to our stakeholders, including people living with WM, caregivers, donors, healthcare providers, and the WM research community, enhances our effectiveness and organizational relevance.

Our Board of Trustees has set a very compelling vision for the organization: **A world without WM.** To achieve this vision, we must grow and keep growing. We can't just settle for the status quo. Our mission statement to **Support and educate everyone affected by WM to improve patient outcomes while advancing the search for a cure**, guided our Board of Trustees in identifying and agreeing on our *Global Imperatives* (strategic priorities) going forward.

By crafting these five *Global Imperatives*, our volunteer and staff leaders have set high expectations:

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

Going forward, we will continue to develop and implement strategic plans that will tell our story to all IWMF stakeholders on a regular basis—outlining the progress we are making, the challenges we are facing, as well as new opportunities as they arise.

We continue to make significant progress. Through collaborative efforts with other like-minded orga-

nizations, innovative initiatives, and the dedication of our IWMF community, we have seen remarkable progress. Each of you, as an IWMF stakeholder, is the ultimate judge of the quality and value of our programs and the impact they make. That motivates us to continually look at our programs and ways of accessing these programs from the "customer" perspective.

By listening to the patient perspective, WM clinician expertise, and staff/board member experience, IWMF identified and initiated a number of new programs during 2023. Here are just a few highlights:

Increased Investment in Research and Scientific Discovery

We continue to support cutting-edge research projects aimed at a better understanding of WM, finding new and improved treatment options, and ultimately finding a cure. As Steven P. Treon, MD, Dana-Farber Cancer Institute, recently responded when asked about the possibility of a cure, "At the end of the day, do I believe there is a cure in sight for WM? Absolutely."

In 2023, IWMF committed 2.5 million USD to support WM-NET, a new multi-institutional network for clinical and research programs dedicated to WM. WM-NET offers a new solution to the clinical trial challenges in WM. This commitment is IWMF's largest single research grant ever. Led by Dana-Farber Cancer Institute (DFCI), this groundbreaking effort brings together 18 major cancer centers and affiliates across the United States to share knowledge and develop clinical trial protocols with the goal of providing patients with more treatment options. In the future, we will work with the IWMF international affiliates and top researchers and clinicians around the world to develop similar networks in other parts of the world.

Through the generosity of donors around the world, IWMF was able to fund additional projects in 2023, totaling 3,157,500 USD, and to establish additional research programs targeted to encouraging novel approaches and developing young investigators so that they can become future global research leaders in WM. Judging from the quality of the research proposals that were submitted and approved, the future looks very bright for the patient and caregiver community.

Expanded Information, Education, and Support Programs

We remain deeply committed to providing valuable resources, support, and services for individuals affected by WM and their loved ones. From our annual Education Forum, support group meetings, either in-person or virtual, educational webinars, information on all aspects of WM, both in print and online, along with personalized guidance and support, we continue to empower and offer hope to the WM community throughout their journey.

Our wellness program initiative provides resources that help find a holistic approach to care. From emotional and physical wellness to helping manage financial issues, we have the resources to help find answers to questions many people may have upon receiving a WM diagnosis, such as, Why me? How did this happen? How long will I live? How will my life, work, relationships change? Wellness resources, curated by IWMF, focus on nutrition and physical wellness. They can assist in self-healing, improving quality of life, and fostering health promotion so that treatments can be more effective with fewer side effects.

We work with our partner organizations to provide possible sources of financial assistance to the global WM community. In addition, we have expanded IWMF's own Patient Travel Financial Assistance program so that no one will be denied access to a second opinion, confirmation of a WM diagnosis, or even simply a WM-related medical appointment because of the cost.

Enhanced Healthcare Provider Education and Awareness

We grew collaborations that made it possible to adapt and disseminate accurate, up-to-date, and independent information to the global WM community. The IWMF-led "Global Patient Initiative" established a partnership with other lymphoma patient organizations to provide a forum to work together to ensure that, no matter where a patient looks for the latest information regarding WM, they find the same consistent guidance and information regarding the disease and available treatments. Along with our partner organizations, we identified the need to provide opportunities for healthcare providers to acquire new knowledge, increase their skill set, and expand their clinical expertise relative to WM. Our goal here is to improve quality of care for people with WM and increase access by increasing the pool of healthcare providers knowledgeable about WM. To this end, we created IWMF's first ever professional education booklet, *Waldenstrom's Macroglobulinemia Essential Information: A Physicians Guide.* It was so well received, we went on to create a comparable resource for nurses, *Waldenstrom's Macroglobulinemia Essential Information: A Nurses Guide.* Both are now available in multiple languages. We also 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. In addition, we are working to expand CME/CE training opportunities to the global healthcare community.

Increased Focus on the Global WM Community

Our commitment to better serve the global WM community has never been stronger. In 2023, we made significant investments to expand our global outreach to ensure that no matter where a patient lives, they could have access to the most current and accurate information on all aspects of WM. We brought together leaders of IWMF International Affiliate organizations from five continents around the globe to talk about making the world a better place for members of the WM community. Together, they shared best practices and learned more about offering life-changing information, education, and support programs. At that same time, in collaboration with the Waldenstrom's Foundation United Kingdom (WMUK), IWMF conducted its first ever European Patient Forum in Amsterdam. In total, 233 patients, caregivers, and healthcare providers participated either at one of our two in-person sites (Amsterdam and Birmingham, UK) or virtually. It was amazing and inspiring to see what can happen when people work together toward a common goal!

Because of the generosity of IWMF's incredible donor community, our overall financial position continues to be strong. Our supporters have seen first-hand the impact that we are making on the lives of people living with WM, and they are confident that their gifts are a very wise investment. Every year since 2018, **Charity Navigator, the nation's largest independent watchdog agency of non-profits, has recognized IWMF with its highest 4-star rating. IWMF received an overall perfect rating of 100, including a perfect 100 rating on accountability and transparency. This demonstrates our commitment to being a good steward of donor dollars!**

Success in today's ever-changing, global environment depends on agility and requires a capacity for rapid change and flexibility. We continue our commitment to these goals for the global WM community and are extremely proud of IWMF's impact on the lives of people living with WM. Yet, we realize there is still so much more to do. For IWMF to achieve our vision of **A world without WM**, we all must work together. As a key stakeholder, please continue to let us know how we're doing. We welcome your advice and guidance along the way.

Thank you again for being with us!

Journey to a Cure: Our Progress and the Way Forward

> ***"The goal of our research program is to improve the quality of life for everyone affected by Waldenstrom's, and, ultimately, to discover a cure."***
>
> — Peter DeNardis, IWMF Board Chair

IWMF has committed more than 30 million USD in research since 2000, funded almost entirely by people living with WM and their families and friends. Because of the generosity of our donor community, researchers know much more about WM and the questions they need to ask, and answer, to find a cure.

Peter DeNardis and Stephen M. Ansell, MD, PhD

As stewards of your investment in research to improve quality of life and find a cure, IWMF leadership carefully considers and chooses research projects based on the potential benefit to the WM community. "So far this focused approach has led to an understanding of the basic biology and genetics of WM, an advance that has been instrumental in the development of the treatments and treatment guidelines currently in use, as well as potential new drugs in the pipeline," said Stephen M. Ansell, MD, PhD, chair of the Division of Hematology and the Enterprise Deputy Director of the Mayo Clinic Cancer Center.

Value of IWMF Funded Research

Your commitment and contributions to IWMF and the research we support have made the life-changing advances in WM research possible:

Zachary R. Hunter, PhD

- In 2011, MYD88, a genetic mutation that occurs in about 90-95% of all WM patients, was discovered through research led by Zachary R. Hunter, PhD, Instructor of Medicine at Harvard Medical School and the Bliss Family Investigator at the Bing Center for WM, Dana-Farber Cancer Institute. "IWMF funding played an important role in the whole genome research that led to finding MYD88. The prevalence of MYD88 mutations in WM has made it easier to diagnose WM," explained Dr. Hunter. "It controls a druggable pathway called Bruton's Tyrosine Kinase (BTK)." Drugs such as ibrutinib, zanubrutinib, acalabrutinib, and pirtobrutinib are examples of oral drugs that work within the BTK pathway.

Steven P. Treon, MD, PhD

- In 2012, based upon a clinical trial conducted by Steven P. Treon, MD, PhD, Director of the Bing Center for Waldenström's Macroglobulinemia Research and an attending physician for medical oncology at Dana-Farber Cancer Institute and Brigham and Women's Hospital, ibrutinib received a Breakthrough Therapy Designation from the Food & Drug Administration (FDA). This was the first Breakthrough Therapy Designation for all cancers—not just blood cancer!
- In 2014, Drs. Hunter and Treon discovered a second mutation in WM called CXCR4. This mutation occurs in 30-40% of WM patients. It affects how quickly BTK inhibitors work and the depth of response that is achieved.
- In 2015, the FDA approved ibrutinib for WM treatment.
- Also in 2015, IWMF partnered with the Leukemia & Lymphoma Society (LLS), the world's largest voluntary health agency dedicated to blood cancer, to develop a roadmap to guide research into WM. The goals of the Strategic Research Roadmap were straightforward: first, to identify the gaps in understanding that were holding back progress toward a cure for WM, and second, to identify and fund the best global research to fill those gaps.
- Subsequent Research Roadmap Summits in 2016, 2017, and 2019 continued to identify the most promising direction for future research.
- In 2021, the FDA approved zanubrutinib for WM treatment. "Of the more than 7,000 rare diseases, less than 10% have an FDA approved treatment. Waldenstrom's has two, thanks to IWMF's aggressive funding of research, dedicated research partners, and pharma partners," said Newton Guerin, IWMF President & CEO.
- By 2023, thanks to contributions of 27 million USD from patients and those who love them, IWMF has funded 95 research projects that have changed the course of the disease. Treatment options have expanded from 4 to 80, with milder side effects. Average life span from diagnosis has rocketed to 20 years and counting.

Today, versed doctors on the front lines tell newly diagnosed patients to expect normal life spans, based on the accelerated pace of WM discovery of optimum patient care.

Research Programs Funded by IWMF

In recent years we have witnessed substantial progress in basic biomedical research and subsequent clinical management of WM. IWMF funded research has been so successful in making these advances in part because of its rigorous requirements for awarding grants, which includes a review by an independent committee composed of select members of the IWMF Scientific Advisory Committee and other experts in the field. The IWMF Board of Trustees also must approve the research grants to be funded, and oversight by IWMF continues after the grants are awarded. Researchers who receive grant awards are required to submit periodic progress reports to the IWMF Research Committee for review and comment.

The IWMF research portfolio includes grants in five categories:

1. The **IWMF-LLS Strategic Research Roadmap Initiative** promotes and supports basic research leading to improved understanding

of the cause, diagnosis, treatment, and cure within five key pillars of WM research.

2. The **Robert A. Kyle Career Development Award** provides funding to support career development of next-generation researchers for WM, including young medical specialists, researchers, and postdoctoral fellows specializing in the area of WM. Recognizing more than 50 years of impactive contributions by Dr. Robert A. Kyle in the field of plasma cell disorders and WM, this award promotes innovative research and is intended to develop knowledge and skills in WM, thereby stimulating research applicable to the development of medical innovations that save and sustain patients' lives.

3. The **IWMF Research Seed Money Initiative** offers investigators around the world opportunities to define objectives and test pilot hypotheses in preparation for larger grant applications through the IWMF-LLS Strategic Research Roadmap Initiative. The seed data from these projects will give investigators a better idea of feasibility and directionality of their future WM research.

4. The **IWMF Enhanced Research Roadmap Initiative** provides new and larger funding for grant proposals that require more time, effort, and resources than the two-year Strategic Research Roadmap Initiative grants.

5. The **IWMF Companion Initiative** funds basic science projects that are clinic-facing, including collaborative projects linked to clinical trials.

For more specific information on these grants and the proposal process, please visit https://iwmf.com/applying-for-a-research-grant/

IWMF Refines Research Focus with Strategic Roadmap

Although the research funded by IWMF prior to 2015 had already made tremendous progress toward improving and prolonging the lives of individuals with WM, the leadership of IWMF recognized that a more strategic approach could result in even greater advancements. In the spring of 2015, with support from the Leukemia & Lymphoma Society (LLS), IWMF held the first Strategic Research Roadmap Summit in New York City. A virtual *Who's Who* among global WM researchers and clinicians, the attendees conceived the Strategic Research Roadmap (the "Roadmap") to guide future research into WM.

The goals of the Roadmap were straightforward: first, to identify the gaps in understanding that were impeding progress toward a cure for WM, and second, to identify and fund the best global research to fill those gaps. The knowledge gaps identified at this and the subsequent three summits led to the establishment of five pillars of WM research as future areas of focus and funding.


Jorge J. Castillo, MD

The most recent IWMF Roadmap Summit was held earlier this year in New York City. Jorge J. Castillo, MD, Clinical Director, Bing Center Clinic, Dana-Farber Cancer Institute, introduced the proceedings: "Bringing together this brain trust gathered here today, excites other groups to see this research as a new frontier. We can learn a lot from what other people have done." Dr. Castillo added, "Ninety percent of WM patients have the MYD88 mutation that is present in other cancers, too, so the global community has their eyes on us because IWMF has driven much of this prog-

ress. IWMF's support of this work is translating into benefits for others with these cancers, so it is critical to continue funding these incredible minds focused on this disease."

Looking Forward: IWMF Continues to Refine the Strategic Roadmap for the Future

In the summer of 2024, a new set of Pillars for WM Research was launched to re-define the next high-value targets on the path to a cure. As research maps the disease process, there are ever more ideas for development of therapeutics.

The new Pillars of WM Research ask these central questions:

- *WM Cell Biology.* How do mutated cells signal to other cells and drive the growth and survival of WM in the bone marrow? This pillar includes the development of novel therapeutic strategies that will interrupt aberrant signaling.
- *T-Cell Based Therapeutics.* How can we further CAR-T therapy for WM? CAR-T therapy is about re-engineering patients' own immune cells to attack mutated cells. This pillar includes novel strategies to promote the immune system's fight against WM mutations and strategies to turn off mechanisms that suppress immune cells from doing their job.
- *Microenvironmental Research.* WM cannot survive without the support of the local bone environment, so what are those WM dependencies? What are the therapeutic ways to block them?
- *Genomic Research (study of genetic material and genetic instructions).* What is the biology of WM evolution from a slumbering state to a symptomatic disease? What mechanisms drive resistance to therapeutic drugs? This pillar includes research about high-risk features.
- *Proteomics.* Distinct from underlying genetics, what is the structure and function of proteins that have an impact on WM signaling pathways and prognostic testing? This pillar includes protein-based research into the causes and treatment of cryoglobulinemia, cold agglutinins, amyloidosis, demyelinating neuropathy, and other complications associated with the uncontrolled proliferation of the IgM protein characteristic of WM.

Newton Guerin and Tom Hoffmann, MD

The second day of the 2024 Summit featured an update on the WM-NET Clinical Trials Network (WM-NET), a collaboration with Dana-Farber Cancer Institute. WM-NET is a multi-institutional network for clinical and research programs dedicated to WM. "This groundbreaking effort represents IWMF's single largest commitment to research to date, 2.5 million USD over five years, and the first initiative to receive funding from IWMF's Accelerate the Cure (ATC) campaign," explains Tom Hoffmann, MD, IWMF Vice Chair, Research.

Led by Dana-Farber Cancer Institute, WM-NET brings together 18 major cancer centers across the country to share knowledge and develop clinical trial protocols with the goal of providing patients with more treatment options.

"In this new era of strategic partnerships and bringing more treatments to more patients, a cure is even more likely," said IWMF CEO Newton Guerin. "This year's combined WM-NET and Strategic Research Roadmap meeting was yet another exciting step forward as the greatest minds in the field met and worked together to create a world without WM."

Looking Forward: New Fundraising Initiative Launched in 2024 to Fund Enhanced Global Research, Education, and Patient Support Initiatives

IWMF's latest fundraising initiative, Accelerate the Cure (ATC) was launched on Leap Year Day, February 29, 2024, as a symbolic leap into the future of medicine by continuing to raise funds to support this research. "If we can raise 31 million USD in five years, we can substantially improve patient outcomes and advance a cure for WM," said Carl Harrington, IWMF Board Trustee and Vice Chair, Fundraising.

In 2024, the IWMF Board of Trustees awarded funding to twelve principal investigators of eleven research awards for a total of 3,157,500 USD. These grants, approved and recommended by the IWMF Research Committee, have been awarded to proposals with the greatest potential for advancing the prevention, diagnosis, and treatment of WM.

One of the first initiatives to be funded by ATC is a 2.5 million USD commitment to support WM-NET. "Given the rarity of our disease, testing new therapies can be difficult due to the relatively small patient population size," says IWMF Board Chair, Peter DeNardis. "Consequently, many treatments for patients with WM result from the findings of relatively small or single-institution studies. Efforts like WM-NET will grow the size of research studies and enable researchers to come together to find significantly better treatments that further improve the quality of life and life expectancy, and expedite the path to a cure."

According to Dr. Castillo, "Clinical trials are the most important way to advance the medical field. Without clinical trial participation, developing now-standard agents such as rituximab, bendamustine, proteasome inhibitors, BTK inhibitors, or BCL2 antagonists would have been impossible." With the help of several strategic partners, such as IWMF, it is expected that WM-NET will activate clinical trials concurrently in multiple centers, accelerating the access to novel agents. WM-NET will also be advised by the patient community and represented by members of IWMF and WM specialists outside of the United States.

WM-NET Participating Facilities

WM-NET is already planning two ongoing efforts to collaborate, including a phase II study evaluating loncastuximab tesirine in relapsed WM and the phase II ZEBRA study (zanubrutinib, bendamustine, rituximab) for WM patients who have never been treated before. "Creating a U.S.-based network of WM clinicians and researchers

will facilitate a more rapid translation of trial and study results into practice, as well as bring clinical trials closer to patients," said Dr. Castillo, who serves as faculty director of WM-NET's steering committee. "We are thrilled that IWMF is partnering with us to ensure we meet our ambitious goals. We're hopeful this network will optimize clinical trial design and foster academic discussion for the benefit of all patients facing this chronic disease." To learn more, visit https://bit.ly/4c3d4wH (article by Dr. Castillo explaining WM-NET in further detail).

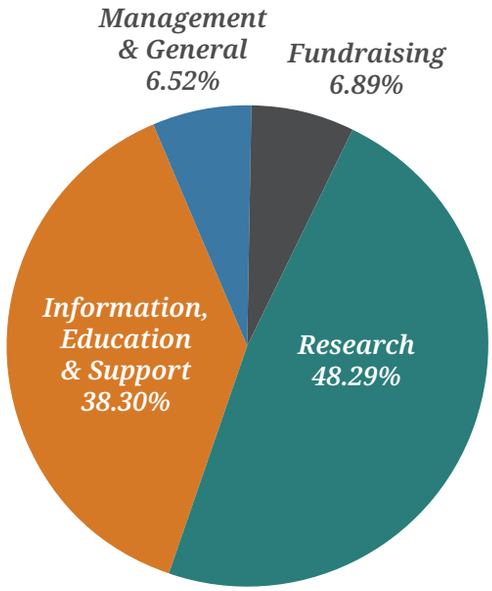
How Funding the Roadmap Research and WM-NET Will Help Us Find a Cure

Since implementing the Roadmap in 2016, IWMF has funded 44 projects with 16.8 million USD—doubling the number of projects funded and tripling its investment of dollars since we began funding research in 2000. To date, research funded by IWMF has already contributed to the accelerated development of treatments and increased life expectancy. Just imagine the impact IWMF can make in the years to come!

Carl Harrington

"The tremendous progress in improving the lives of individuals with WM and their families and toward finding a cure is possible because of the generosity of our community," said Carl Harrington, President/Board Chair Emeritus. "Your dollars are funding the best minds in the world to find a cure. But to keep them working, we need to raise an additional 31million USD by 2028. If we all pull together to do this, we can realistically expect further improvements in our quality of life, longer lives, and even a cure."

Your Support Is Invested Wisely



This fiscal year 2023, IWMF has raised **$3.3 million** to support our mission and operations.

We have spent **$3.5 million** or **86.59%** 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 12/31/23 (US dollars)

Revenue:

Campaign Contributions	$3,068,888
Other Income	$12,327
Net interest and dividend Income	$226,174
***Total Revenue:**	***$3,307,390***

Expenses:

Research	$1,967,148
Information, Education & Support	$1,560,373
Total Program Services	***$3,527,521***
Management and General	$265,656
Fundraising	$280,524
Total Expenses:	***$4,073,701***
Change in Net Assets	***($766,311)***

* Currently the BRHS has identified potential gifts totaling $11,484,410. 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 $5,857,976. Additionally the IWMF has approved future research project NOT yet under contract in the amount of $115,309.

Consolidated Balance Sheet as of 12/31/23

Revenue:

Cash and cash equivalents	$7,383,049
Prepaid Expenses and other assets	$176,223
Contributions and other receivables, net	$823,953
Fixed Assets, net	$53,938
***Total Assets:**	***$8,437,163***

Liabilities:

Accounts payable & accrued Expenses	$292,516
Deferred revenue	$21,500
Other long term liabilities	$29,197
***** Total Liabilities***	***$343,213***

Net assets:

Without donor restriction	$6,300,018
With donor/time restriction	$2,560,241
Net Income	($766,311)
Total Net Assets	***$8,093,947***
Total Liabilities and Net Assets	***$8,437,160***

Ben Rude Heritage Society

The Ben Rude Heritage Society recognizes those who have made provisions for a future gift to IWMF, such as a bequest, listing 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:

Ronald Allen
Anonymous
Jean-Marc* and Sarah Audibert
Paul Awes
C. Edwin Baker*
Jack Baker
Jane Ballard In Honor of Shirley Ganse
Janet Bausser*
David M. Benson
Beverly J. Bloss
Elsa and Gary Bradley
Arlou Brahm*
Ronald and Mary Jane Branscome
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Lenny Martin
Judith Ann May
Katherine E. McCleary and K. Edward Jacobi*
Kathleen L. Miner
Anne and Pedro Mitro♦
Eleanor Moore*
Maynard Morris
Cynthia Muelling
Sam* and Gail Murdough
Guido and Ida Neirotti*
Barry Nelson
Linda Nelson
Brandt* and LaVey Norquist
James and Bette Ortoleva
Paula Pangle
Howard F. Prass*
Alan Prestell*
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Sharon Resnik*
Paul and Janice Rippas
Roger* and Barbara Robinette
Margaret Rockelman*
Joel and Laura Rosenblit
Laurie Rude-Betts♦
Cynthia Ruhl
Andy Ruland
Robin and Ronald Rutter
Susan Beatrice Santa Maria*
Naomi and Shimon Schechter
Elmo R*. and Dolores E. Schmid*
Karen Elizabeth Senecal
Michael and Carol Sesnowitz
Allan Shaw*
Susan Sherwin
Dr. Guy R. Sherwood
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Judith Lee Sterling and Leslie Charles Wilson
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John and Diane Tiplady
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Mathilde Johanna van Gogh*
Tamara Vincent
Dr. Jacob Weintraub
The White Family Trust
Karen Wickert
Bette Kay Wieland
Virginia A. Williams*
Lisa Wilson
Arthur Winter
Lisa Wise
Penni Wisner
James P. Yeager*
Ralph Zuckerman*

*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 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:

David and Janet Bingham
Research Fund of the IWMF

Elting Family
Research Fund of the IWMF

The Lynn M. Fischer
Research Fund of the IWMF

Hamberg Family
Research Fund of the IWMF

Robert Douglas Hawkins
Research Fund of the IWMF

K. Edward Jacobi
Research Fund of the IWMF

Michael and Rosalie Larsen
Research Fund of the IWMF

Leukaemia Foundation of Australia

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Financial and other information about The International Waldenstrom's Macroglobulinemia Foundation, Inc. can be obtained by writing the Foundation at 6144 Clark Center Avenue, Sarasota, FL34238. In addition, several states where The International Waldenstrom's Macroglobulinemia Foundation, Inc. is required to file financial information each year also require the following disclosures: Colorado: Colorado residents may obtain copies of registration and financial documents from the office of the Secretary of State, (303) 894-2680, http://www.sos.state.co.us/. Florida: Registration No. CH33403. A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE, WITHIN THE STATE, 1-800-HELP-FLA OR VIA THE INTERNET AT http://www.FloridaConsumerHelp.com. Georgia: A full and fair description of the programs and activities of The International Waldenstrom's Macroglobulinemia Foundation, Inc. and its financial statements are available upon request at the address indicated above. Maryland: For the cost of postage and copying, documents and information filed under the Maryland charitable solicitation law can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401, (800) 825-4510. Michigan: MICS No. 45029. Mississippi: The official registration and financial information of The International Waldenstrom's Macroglobulinemia Foundation, Inc. may be obtained from the Mississippi Secretary of State's Office by calling 1-888-236-6167. Registration with the Secretary of State does not imply endorsement by the Secretary of State. New Jersey: INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. New York: A copy of the latest annual report can be obtained from the organization or from the Office of the Attorney General by writing the Charities Bureau, 120 Broadway, New York, NY 10271. North Carolina: Financial information about this organization and a copy of its license are available from the State Solicitation Licensing Branch at 1-888-830-4989 (within North Carolina) or 919-807-2214 (outside of North Carolina). The license is not an endorsement by the State. Pennsylvania: The official registration and financial information of The International Waldenstrom's Macroglobulinemia Foundation, Inc. may be obtained from the Pennsylvania Department of State by calling toll-free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement. Virginia: Financial statements are available from the State Office of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218. Washington: The notice of solicitation required by the Charitable Solicitation Act is on file with the Washington Secretary of State, and information relating to financial affairs of The International Waldenstrom's Macroglobulinemia Foundation, Inc. is available from the Secretary of State, and the toll-free number for Washington residents: 1-800-332-4483. West Virginia: West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. REGISTRATION IN THE ABOVE STATES DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION OF THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION, INC . BY THE STATE.

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