IWMF

International Waldenstrom's Macroglobulinemia Foundation

ANNUAL REPORT 2024

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My name is **Paul Kitchen**. I became Chair of the International Waldenstrom's Macroglobulinemia Foundation (IWMF) in 2024. Like everyone else on the IWMF Board, I have a very personal connection to our disease. My story goes back to the 1970's when my mother was diagnosed with WM. Back then, we knew almost nothing about WM and there were no treatments. My mother passed away in just a few years, never having met anyone else with WM. Thanks to the IWMF, my story is completely different and yours will be too. My full story is HERE if you want to read it.

I mention my story because every IWMF Board member has a similar kind of connection. We all have "skin in the game" as do all our volunteers around the world. This deep personal knowledge and experience with WM drives everything we do and enables us to accomplish amazing things.

IWMF: A remarkable organization

The IWMF is a remarkable organization. We are the only global organization dedicated solely to Waldenstrom's macroglobulinemia (WM). We are a patient-founded and patient driven nonprofit with a simple but compelling vision and mission.

- *IWMF Vision: A world without WM.*
- *IWMF Mission: To support and educate everyone affected by WM to improve patient outcomes while advancing the search for the cure.*

Our promise to everyone affected by WM is that no matter who you are or where you are **with the IWMF you are never alone.**

In the pages that follow you can learn

1. What made 2024 a remarkable year for IWMF
2. How we shaped our annual research investment
3. How we steward your support: The Financials
4. How much we value the Ben Heritage Society

I encourage you to read on. I hope you'll come away encouraged with the rapid progress we are making and how together we will accomplish our vision of a World without WM.

With hope,

Paul Kitchen,
IWMF Board Chair

2024 was a remarkable year for the IWMF

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There were so many positive accomplishments in 2024, I could write 1,000 pages but I'm going to limit myself to four amazing achievements:

1

We introduced the Accelerate the Cure Campaign: A Bold Leap Forward on Leap Day

On Leap Day — February 29, 2024, the IWMF announced the **Accelerate the Cure campaign:** A bold effort to raise $31 million in five years to accelerate progress towards A World Without WM! This campaign was designed to move us closer to the ultimate goal that we all dream about: a cure for WM.

Is a cure even possible?

In a word, yes! Read these inspiring statements from two of the leading WM experts in the world. To let the words sink in, consider reading them out loud.

Here's what **Dr. Steven Treon** from the Dana Farber Cancer Institute says: *"At the end of the day, do I believe there is a cure in sight for WM? Absolutely."*

And don't miss Dr. Treon's hopeful and inspiring video.

Click Here

Another WM "doc-star," **Dr. Stephen Ansell** from the Mayo Clinic says: *"The generous support of IWMF has set the stage for an acceleration of research towards a cure."*

2

We achieved record revenue in 2024 of nearly $4.5M

2024 was a remarkable year in fundraising. We raised $4,490,494, up 36% or nearly $1.2M vs. 2023. For perspective, ten years earlier in 2014, we had set a record at that time of $1,695M. So, in 2024, we raised 265% or about $2.8M more than we did 10 years earlier. Since approximately 95% of IWMF revenue comes from WM patients and the people who love them, thank you! We receive no financial support from any government anywhere in the world. If we want to find a cure, it's up to us to all donate whatever we can.

3

We funded the most research into WM since the inception of IWMF

Powered by Donors: The Next Chapter in WM Research. In summer 2024, IWMF launched a bold new research blueprint—the updated Pillars of WM Research. This strategic direction opens up frontiers to stop WM before it starts, reverse immune resistance, target high-risk mutations, and prevent complications like cryoglobulinemia and neuropathy.

The 2024 Research Pillars

This is how cures are built: one smart grant at a time, backed by one determined donor at a time.

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The new Pillars of WM Research tackle the disease from all sides. **WM Cell Biology** studies how cancer cells grow, survive, and interact with other cells in the bone marrow—revealing new ways to stop their spread.**T-Cell–based Therapeutics** advances immune strategies, like CAR-T, that retrain the body to find and destroy WM cells. **Microenvironmental Research** targets the bone marrow environment that helps WM cells survive. **Genomic Research** uncovers the mutations that turn WM from quiet to active and make it harder to treat. **Proteomics** looks beyond genes to the harmful proteins that drive complications like cryroglobulinemia, neuropathy, and amyloidosis. Together, these five Pillars chart a smarter path forward—toward better treatments, better answers, and a cure.

2024 Grant Awards: Take a look! The Enhanced Roadmap Grant

We deeply appreciate the investment of the Rosen Family Foundation and the Donald and Alison Weiss Family Research Fund in our biggest research grant ever—at $1.5 million for three years. Dr. Zachary Hunter at Dana-Farber Cancer Institute and Patrizia Mondella of Mayo Clinic form a powerhouse that bridges the best of genomic science, clinical medicine, and drug discovery.

This team will further expose the hidden subtypes of WM and uncover why patients respond so differently to treatment. Their study will probe the role of a suspect gene (TNFAIP3), trace early cancerous clones before symptoms begin, and test targeted drugs designed to stop WM before it spreads. With this work, the team moves the field toward personalized treatment. **This isn't incremental science. It's a game-changer.**

Other Roadmap Grants

Our four-year, $480,000 Roadmap Grants are designed to be catalytic. They support deep exploration of WM's dependencies—including the bone marrow micro-environment and the molecular machinery WM cells need to survive.

Dr. Aldo Roccaro, MD, PhD, ASST-Spedali Civili di Brescia

Dr. Roccaro is diving deep into the bone marrow environment that helps WM grow. His research focuses on mesenchymal stromal cells—special support cells that may be "coaching" WM cells to survive and spread. By comparing these cells in healthy individuals, patients with IgM MGUS, and those with WM, he aims to find the critical interactions that fuel disease progression. Dr. Roccaro will map how these stromal cells influence WM—and target the ones doing the most harm. The goal: new therapies that cut off WM's support system at the source.

Dr. Josephine Vos, MD, PhD, AMC Medical Research

The WM-VOICE study focuses on what patients with Waldenström value most in their treatment. Researchers from the hematology department of Amsterdam UMC are conducting this study, in collaboration with Waldenström experts and patient organizations from the United Kingdom, the United States of America, Australia, Canada, and the Netherlands. WM treatments vary regarding efficacy, side effects, administration, and duration. An improved understanding of patient preferences may guide tailoring treatment to the individual and set priorities in drug development and trial design in the future.

Kyle Awards

Our two-year Robert A. Kyle Career Development Awards are intended to foster a new generation of talented WM researchers.

Dr. Tina Bagrtuni,
National and Kapodistrian,
University of Athens, Greece

Development of drug resistance is currently one of the main challenges plaguing anti-cancer therapy and is often responsible for cancer progression and treatment failure. Dr. Bagratuni intends to explore the evolution of the ibrutinib-resistant proteome in WM patients undergoing ibrutinib treatment. With screening of blood plasma proteins, she hopes to detect biomarker proteins associated with the development of resistance, with the goal of developing a less invasive way than bone marrow biopsies to monitor ibrutinib treatment in WM patients.

Dr. Filip Garbicz,
Dana-Farber Cancer Institute, Boston, US

Although the MYD88 L265P mutation is common in WM and certain lymphomas, it isn't enough on its own to cause cancer. Dr. Garbicz believes a missing piece—literally—is a deletion on chromosome 6 (6q), found in nearly half of WM cases. His research will test whether this deletion is a key driver of disease by engineering mouse models to mimic it, helping to reveal the biological pathways that turn early mutations into full-blown cancer.

Dr. Christina Jimenez, PhD,
University Hospital of Salamanca, Biomedical Research Institute of Salamanca, Spain

Dr. Jimenez is tackling one of the biggest mysteries in WM: why and how the disease progresses. Dr. Jimenez intends to characterize the genomic alterations and the tumor micro-environment of WM cells in WM symptomatic patients and correlate them with the patients' clinical characteristics, treatment responses, and prognosis.

Dr. David Cordas dos Santos, MD
Dana-Farber Cancer Institute

Dr. Cordas dos Santos, is taking aim at the earliest stages of Waldenstrom macroglobulinemia (WM)—before symptoms begin. His research focuses on patients with IgM MGUS and smoldering WM, conditions that often come before full-blown disease. Today, these patients are simply watched, not treated. But what if we could predict who's most likely to progress—and step in earlier?

Using cutting-edge tools like spatial transcriptomics and mass cytometry imaging, Dr. Cordas dos Santos will create detailed maps of the bone marrow's immune environment to find biomarkers that reveal risk. The goal: to protect patients before WM takes hold.

SEED Grants

The Seed Money Initiative is a fast-start grant from IWMF —designed to spark bold new ideas in WM research. It gives investigators around the world one year to test an innovative concept or gather early data. If promising, these findings often serve as the foundation for larger, longer-term studies. Our WM community of donors funded these grants at USD $90,000.00.

Dr. Jennifer Kimberly Lue,
Memorial Sloan Kettering Cancer Center

Dr. Lue is testing a promising new drug, KT-413, that degrades a key protein in the MYD88 pathway (called IRAK4), potentially killing WM cells more effectively. She'll also test whether this drug works even better when combined with an existing therapy, venetoclax. This study could open a new door to treatment.

Dr. Erna Magnusdottir,
Associate Professor, University of Iceland

While current cell lines and mouse models have taught us a lot, they fall short when it comes to one of the most critical factors in this disease: the bone marrow micro-environment. Using cutting-edge stem cell technology, Dr. Magnusdottir is creating bone marrow "organoids"—

miniature, living versions of human bone marrow—that can be seeded with WM cells. These organoids will allow scientists to watch in real time how WM and its surroundings feed off each other. It's bold, boundary-pushing science—and IWMF donors help get this off the ground.

From Lab to Blood

Fueled by our WM donor community, **Dylan Gagler** (NYU Langone Health) published a landmark study in Blood—the flagship journal of the American Society of Hematology—November 2024. Blood has shaped the science of blood cancers since 1946.

In a groundbreaking study, supported by our IWMF Kyle Grant for Young Investigators, Gagler's team found that Waldenstrom's macroglobulinemia (WM) seems to come in three distinct biological forms. All start from a specific type of immune cell—called a memory B-cell—that has multiplied abnormally and gotten stuck partway through its development into a plasma cell. These three subtypes—B-cell-like, plasma-cell-like, and an "in-between" type—each have their own genetic patterns and cell behavior. This new understanding could help doctors predict how the disease will progress and point toward more personalized treatments.

4

We dramatically strengthened the IWMF Board of Trustees and our Scientific Advisors

We have amazing volunteers around the globe helping the IWMF "punch above its weight." These volunteers include our compassionate Support Group leaders, the IWMF Torch staff, our Research Committee that reviews the progress reports for each of our research projects, the leaders in each country we're in, the Publications Committee and the wise and compassionate volunteers who staff our IWMF Facebook pages, IWMF Connect and Lifeline. There are just so many people who give freely of their time and knowledge to help others. But right now, I want to introduce you to the IWMF Board of Trustees.

Our Board of Trustees: Leading with Expertise. Driven by Personal Stakes.

The IWMF Board of Trustees is not your typical nonprofit board. These are accomplished leaders—executives, clinicians, entrepreneurs, and scientists—who bring world-class expertise to our mission. But what truly sets them apart is this: every single trustee either lives with Waldenstrom macroglobulinemia (WM) or stands beside someone who does. They know what it means to wait for test results. To ask hard questions. To hope for a better treatment—or a cure.

Their commitment is total. They donate their time, their professional skillsets, and their financial resources. They show up—in meetings, in support groups, in research planning sessions—not just as board members, but as members of the WM community. That's why their leadership matters. That's why they push for results. And that's why you can trust that IWMF is all-in, from the inside out.

Read about our amazing Board of Trustees

HERE

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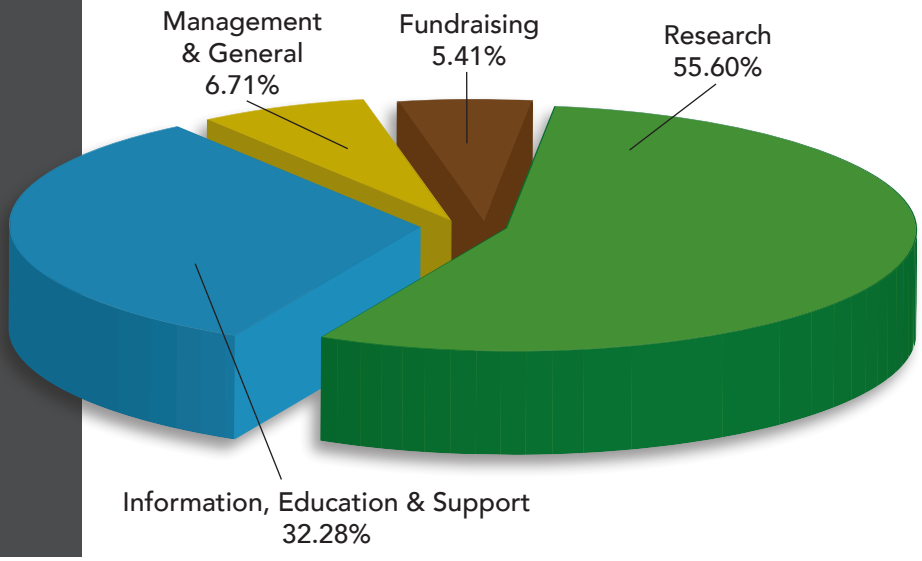
Your Support is Invested Wisely

This fiscal year 2024, IWMF raised $4.5 million to support our mission and operations.

We have spent $4.8 million or 87.86% of our expenses on specific programs designed to find new treatments for WM and improve the lives of patients and their families.

January – December 2024 Expenses



Consolidated Statement of Activities as of 12/31/24 (US Dollars)

Revenue:	
Campaign Contributions	$4,158,217
Other Income	$26,797
Net Interest and Dividend Income	$305,481
***Total Revenue:**	**$4,490,496**
Expenses:	
Research	$3,060,062
Information, Education & Support	$1,779,479
Total Program Services	**$4,839,541**
Management and General	$369,147
Fundraising	$297,925
Total Expenses:	**$5,506,613**
Change in Net Assets	**($1,016,117)**

The IWMF is proud to receive a 4-star rating from Charity Navigator, the nation's largest independent rater of non-profits. IWMF received an overall perfect rating of 100 including a perfect 100 rating on accountability and transparency. You can invest with confidence with IWMF, knowing we will be excellent stewards of your donation.

Consolidated Balance Sheet as of 12/31/24

Assets:	
Cash and Cash Equivalents	$6,040,635
Prepaid Expenses and Other Assets	$233,404
Contributions and Other Receivables, Net	$1,173,192
Fixed Assets, Net	$30,829
Total Assets:	**$7,478,061**
Liabilities:	
Accounts Payable & Accrued Expenses	$400,228
Deferred Revenue	$0
Other Long-term Liabilities	$0
****Total Liabilities**	**$400,228**
Net Assets:	
Without Donor Restriction	$6,819,274
With Donor/Time Restriction	$1,274,676
Net Income	($1,016,117)
Total Net Assets	**$7.077,833**
Total Liabilities and Net Assets	**$7,478,061**

**Currently the BRHS has identified potential gifts totaling $14,867,506. Since these contributions can be rescinded at anytime they are not recorded as revenue.*

***The IWMF has committed to future research grant projects under contract in the amount of $5,907,959. Additionally the IWMF has approved future research project NOT yet under contract in the amount of $277,500.*

2024
Ben Rude Heritage Society Members

The Ben Rude Heritage Society recognizes those who have made provisions for a future gift to IWMF, whether through a bequest, a life insurance policy or a qualified plan asset like a 401k or IRA. Legacy gifts are a vital part of IWMF's financial future—totaling $5,221,067 through 2024. This year, 31 new members joined—the most ever in a single year—committing over $4 million in future gifts. We are deeply grateful to the following members—your generosity develops a future where the next generation is spared WM.

Ron Allen
Jean-Marc* and Sarah Audibert
Paul Awes
Jack Baker
C. Edwin Baker*
Anonymous
Jane Ballard In Honor of Shirley Ganse
Janet Bausser*
David M. Benson
Beverly J. Bloss
Elsa and Gary Bradley
Arlou Brahm*
Marjorie Janeen Brannan
Ronald and Mary Jane Branscome
William O. and Ellen Kaner Bresnick✦
L. Don and Mary Brown
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John Button*
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Peter Carr
Gerald Preston Clancey*
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Jean Ellis*
Raymond and Betty Fishman*
Gregory Fitzwater and
Marilyn Zollner-Fitzwater
Glenda and Richard Fredericks
Marlyn Friedlander and Gilbert Scherer
Cindy L. Furst*
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in honor of John Swisher
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John Kearney
Shan Elizabeth Keary*
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Nancy Kerr*
Thomas Keys*
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Glenn and Marcia Klepac
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Dr. Robert A. and Charlene M. Kyle
Anonymous
Michael and Rosalie Larsen*
Anita Lawson
Gay L. Lesmister*
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Robert J. Lynch*
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Judith Ann May
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Katherine E. McCleary and
K. Edward Jacobi*
Kathleen L. Miner
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Maynard Morris
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Linda Nelson Brandt* and LaVey Norquist
James and Bette Ortoleva
Paula Pangle
Howard F. Prass*
Alan Prestell*
Barbara Qualley*
Marguerite C. Regan, PhD*
Sharon Resnik*
Paul and Janice Rippas
Dr. and Mrs. Charles Ritz
Roger* and Barbara Robinette
Margaret Rockelman*
Joel and Laura Rosenblit
Laurie Rude-Betts✦
Cynthia Ruhl
Andy Ruland
Debora Jane Sanberg
Jeffrey Sanberg
Susan Beatrice Santa Maria*
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Judith Lee Sterling and
Leslie Charles Wilson
Eileen Sullivan and Gary Shrager
John and Diane Tiplady
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The White Family Trust
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Virginia A. Williams*
Lisa Wilson
Lisa Wise and Steve Weiner
Penni Wisner
James P. Yeager*
Ralph Zuckerman*

**Deceased*
✦Founding Member

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