



# RESEARCH: OUR SEARCH FOR A CURE

The IWMF is committed to creating a world without WM by finding a cure. Since 2000, the IWMF has funded over \$23 million in global WM research. This has been made possible by generous individual and corporate gifts.

Starting in 2015, the IWMF partnered with the Leukemia & Lymphoma Society (LLS) to sponsor a Strategic Research Roadmap Initiative to develop our research strategy. This Initiative resulted in agreement to focus WM research in five areas:

- **SIGNALING** - Understand the pathways WM cells use for communication.
- **IMMUNOLOGY/IMMUNOTHERAPY** - Determine how we can use our own immune system to fight WM.
- **TUMOR MICROENVIRONMENT** - Understand how the bone marrow/tumor environment affects WM cells.
- **“OMICS”** - Expand our knowledge about genomics, epigenomics, and mutations in WM cells.
- **IGM MONOCLONAL GAMMOPATHY OF UNDETERMINED SIGNIFICANCE (MGUS)** - Discover what molecular changes drive progression from benign MGUS to WM.

The IWMF-LLS Strategic Research Roadmap Initiative provides the framework for a global research program. Under the Roadmap Initiative, the IWMF annually awards new Roadmap research grants. Each project is funded up to \$480,000 over two years.

Beginning in 2021, the IWMF provided funding for young investigators to support career development of next-generation researchers for WM. These grants are for \$157,500 over two years.

Beginning in 2022, the IWMF established a new Research Seed Money Initiative. These grants are intended to give investigators around the world the chance to define objectives and test pilot hypotheses in preparation for larger grant applications through the IWMF/LLS Strategic Research Roadmap Initiative. Each grant is for a total of \$90,000 over one year.



★★★★

**THE IWMF IS PROUD TO RECEIVE A 4-STAR RATING FROM CHARITY NAVIGATOR, THE LARGEST INDEPENDENT RATER OF NON-PROFITS IN THE UNITED STATES.**

THE IWMF RECEIVED AN OVERALL RATING OF 95.47 AND A PERFECT 100 RATING ON ACCOUNTABILITY AND TRANSPARENCY. THIS MEANS YOU CAN DONATE WITH CONFIDENCE.

## OUR VISION:

A world without WM  
(Waldenstrom's macroglobulinemia)

## OUR MISSION:

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

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*Julie R., IWMF Community Member*

# IMAGINE...

## A WORLD WITHOUT WM

(Waldenstrom's macroglobulinemia)



  
**21,000+**  
COMMUNITY  
MEMBERS

  
**90+**  
COUNTRIES

  
**70+**  
SUPPORT  
GROUPS  
GLOBALLY

  
**80+**  
RESEARCH  
PROJECTS

  
**\$23M+**  
IN RESEARCH



## ABOUT THE IWMF

The International Waldenström's Macroglobulinemia Foundation (IWMF) is a patient-founded and patient-driven, international nonprofit organization with a simple but compelling vision and mission.

**OUR VISION:** A world without WM (Waldenström's macroglobulinemia)

**OUR MISSION:** Support and educate everyone affected by Waldenström's macroglobulinemia (WM) while advancing the search for a cure.

Headquartered in Sarasota, FL, the IWMF has international affiliates on five continents and serves people affected by WM across the globe. Founded in 1994 with only 21 patients, we are proud that today more than 21,000 people in over 90 countries look to the IWMF for information, education, and support.

## ABOUT WM AND LPL

Waldenström's macroglobulinemia (WM) is a non-Hodgkin's lymphoma, or cancer of the blood. Ninety-five percent of all lymphoplasmacytic lymphoma (LPL) is WM. WM is a rare cancer seen only in approximately three to five per million people per year, with about 1,500 new cases diagnosed in the US each year.

Although WM is currently incurable, patients are living longer and enjoying higher-quality lives with deeper remissions and fewer side effects due, in part, to critical research funded by the IWMF.



# LIVING WITH WM: YOU ARE NEVER ALONE WITH THE IWMF!

Although WM is a rare disease, with the IWMF, you are never alone. We provide educational, wellness, and support programs, so patients understand WM and can get support from fellow WM patients who share their same rare diagnosis. Publications are available in multiple languages\* and our website reaches global patients in more than 100 languages. All IWMF programs are absolutely free, with the exception of the annual two-day educational forum. Among our programs are:

- The IWMF website, [IWMF.COM](http://IWMF.COM), provides up-to-date information about WM, direct access to all of our programs, and multiple ways to connect to the WM community.
- **INFO PAKs** for newly diagnosed patients provide information designed especially for those who are learning about WM for the first time. Each INFO PAK includes IWMF publications to help newly diagnosed patients and their caregivers understand WM, learn how to treat it, and live with it.\*
- US and international **SUPPORT GROUPS**. Over 70 support groups throughout the world enable patients and caregivers to meet in person or virtually, to learn from expert guest speakers, share information, create lasting bonds, and connect with the local WM community close to home.
- **LIFELINE** is a telephone and email support program offered by volunteer WM patients and caregivers. These peer mentors share their experiences to help others navigate their WM journey.
- **IWMF CONNECT** is an online group discussion forum. Available 24/7, it allows patients and caregivers to ask questions and get answers from fellow patients and caregivers.
- **IWMF NEWS**, information, and videos on Facebook, LinkedIn, Twitter, and YouTube.

  
**IMAGINE**  
— A CURE —



- **PUBLICATIONS** about WM feature a series of booklets, treatment options guides, and fact sheets that can be downloaded in multiple languages for free at [IWMF.COM](http://IWMF.COM).\*
- The **IWMF TORCH** quarterly magazine is available online and in print. Each issue keeps IWMF community members informed about WM progress, research activities, treatments, events and programs, nutrition, mental health, and more.
- The **IWMF EDUCATIONAL FORUM** is a unique annual opportunity for patients and caregivers to come together in person or virtually, to learn about WM from world-renowned specialists. Presentations are recorded and made available on the IWMF website. This information-packed weekend event is held at different locations across the US.
- IWMF **eNEWS** delivers timely "need to know" information to our community members' email inboxes about WM and the IWMF.
- **WORLDWIDE DIRECTORY OF WM PHYSICIANS** catalogs well-known cancer centers and physicians/researchers who are experts in WM. All physicians included in our **PHYSICIANS DIRECTORY** have agreed to be available for consultation and second opinions to patients, as well as other physicians.
- **STORIES OF HOPE** remind you that you are not alone! Living with a rare cancer may make some patients feel like they are all alone. Many WM patients have shared their interesting and inspiring stories with us so we can share them with you.

Please visit the IWMF website at [IWMF.COM](http://IWMF.COM), email us at [INFO@IWMF.COM](mailto:INFO@IWMF.COM), or call our friendly office at **941-927-4963**. We're here to help and we hope that you will reach out!



\*Most available in English, Chinese (Simplified and Traditional), French, German, Italian, Norwegian, Polish, Portuguese, Spanish, and Finnish.