International Waldenstrom's Macroglobulinemia Foundation

6144 Clark Center Avenue
Sarasota, FL 34238
T: 941-927-4963
www.iwmf.com
Email: info@iwmf.com

Dear Friend,

Welcome to the WM family.…While this isn't a family that you ever wanted to join; we are happy you found us. The first thing to know is that *you are not alone.*

The International Waldenstrom's Macroglobulinemia Foundation (IWMF) is a patient-founded, non-profit organization that supports and educates everyone affected by Waldenstrom's macroglobulinemia (WM) to improve patient outcomes while advancing the search for a cure. Established in 1998, IWMF has grown to more than 25,000 individuals from 90 countries. In the context of a rare disease with just 1,500 to 3,000 new annual US diagnoses, 1,600 new individuals joined IWMF last year. We are the only organization devoted exclusively to patients with WM and their caregivers… that is, to you.

We are sharing this Info Pak to help you better understand WM. The good news is that WM is a slow-growing cancer that is considered a model cancer for researchers to study. You are supported by a top-of-class nonprofit determined to advance the search for a cure by leaps and bounds. **Dr. Steven Treon, of Dana-Farber Institute, says:** ***"Once we do a better job at shutting down the signaling of that mutated MYD88 gene, we will find that cure. At the end of the day, do I believe there is a cure in sight? Absolutely."***

IWMF is *the* organization that coordinates the efforts of leading scientist-physicians globally to define the fastest path to a WM cure. Having funded 100 research projects, we have made quantum leaps in understanding WM genetic mutations and their biology. The research spawned therapies that extended patient lifespans by decades.

So, who funds this research? We are fully dependent on those with WM and those who love them to fund our Accelerate the Cure Campaign. Governments simply don't fund rare diseases.

We suggest you take three actions:

#1: **Join the IWMF e-news** to receive emailed updates on Accelerate the Cure advances, new clinical trial opportunities, US and European educational forums, and patient/caregiver support. As a community member, you can receive the *IWMF Torch*, a quarterly magazine with articles about research progress, treatment advances, events, and profiles of other WM patient journeys.
#2: **Support —Take advantage of our patient network.** We have 74 Patient Support & Affinity Groups worldwide, and IWMF Connect and Facebook discussion groups have over 10,000 members**.** Prefer the phone? **Lifeline** enables you to connect 1:1 with a peer mentor. For second opinions, we have a **Physicians Directory** of worldwide WM experts. Our **Wellness Program** can help you thrive with this rare disease.
#3: **Donate to Accelerate the Cure**. Annual donations are investments in your health. Fund research that unpacks the biological mechanisms of cancer cell growth, or fund WM-NET, a network of 22 academic-centered hospitals coordinating WM clinical trials. Every dollar counts. It's up to us to find that cure!

We are always seeking volunteers who can translate science into layperson language, engage in fellow patient support, or join strategic thinkers on our Board of Directors.

Best wishes for a long, happy life,

Paul Kitchen
IWMF Chair, Board of Trustees