International Waldenstrom's Macroglobulinemia Foundation

1994-2024: The Compelling Track-Record of a Unique Patient-Doctor Alliance

The International Waldenstrom's Macroglobulinemia Foundation (IWMF) began in 1994, through the effort of a patient and pharmacist who had Waldenstrom's macroglobulinemia (WM), Arnie Smokler. Disease symptoms were identified by Dr. Jan G. Waldenstrom of Sweden in 1943—some 50 years earlier—but little progress was made in intervening years. Scant disease information was available, and when Arnie came along, drugs were applied without specific knowledge of WM—if patients were ever diagnosed. Life span was unknown and short.

The fledgling IWMF joined doctors in a first WM workshop, in the year 2000. Two years later, they established an official scientific definition of WM at an International Workshop in Greece. Over the next 22 years, progress exploded. The patient-driven IWMF became the international focal point for WM communication, education, and research. Patients, and those who love them, contributed USD 27 million to 95 research projects, and IWMF changed the course of the disease. Treatment options expanded from 4 to 80, with milder side effects. Average life span from diagnosis rocketed to 20 years and counting. Today, well-versed doctors on the front lines tell newly diagnosed patients to expect normal life spans, based on our accelerated pace of WM discovery and delivery of optimum patient care.

This momentum includes:

2008: ***Development of two WM tissue banks, a first mouse model and three cell lines.***
IWMF & LEUKEMIA & LYMPHOMA SOCIETY.
Triples the tools for disease study.

2011: ***Discovery of MYD88 L265P—a genetic mutation shared by 90-95% of all WM patients.***
DR. ZACHARY HUNTER, IN DR. STEVEN TREON'S DANA FARBER LAB.
Critical event—spawns targeted treatment unique to WM.

2012: ***Development of the drug ibrutinib. Earns FDA designation as "Breakthrough Therapy."***
DR. TREON
1st WM drug; 1st cancer drug to earn fast-tracked status for promising treatment; Released 2015.

2014: ***Discovery of CXCR4 mutations shared by 30-40% of WM patients.***
DRS. HUNTER & TREON
Triggers research about secondary mutations that help abnormal cells multiply.

2015: ***Launch of Strategic Research Roadmap.***
IWMF WITH LEUKEMIA & LYMPHOMA SOCIETY
Doubles the research projects; triples the spending.
Opens up exploration of bone microenvironment, genes, and complicated cancer cell signaling.

2021: ***FDA-approval of 2nd drug specific for WM – zanubrutinib.***
BEIGENE SCIENTISTS
Only 10% of 7,000 National Institutes of Health-listed rare disorders have even one approved drug, let alone two.

Today: **The International Workshop has grown from 18 to 700+ medical experts.** The roadmap to a cure is reaffirmed.
A new USD 31 million campaign deepens the focus, propels results.

> ***"At the end of the day, do I think there is a cure in sight for WM? Absolutely."***
>
> *Dr. Steven Treon, Dana Farber Cancer Institute, 2024*