

## SERVICES AVAILABLE TO MEMBERS AND FRIENDS OF THE IWMF

Info Paks for Patients and for Medical Professionals – These contain several of our most popular publications, as well as information about joining the IWMF, and are directed to newly diagnosed WM patients and to the medical professionals who take care of them. They are available free of charge and are mailed upon request from the IWMF Business Office (phone 941-927-4963 or email office@iwmf.com) or through our website at <a href="https://iwmf.com/iwmf-info-for-patients-and-caregivers/">https://iwmf.com/iwmf-info-for-patients-and-caregivers/</a>

Annual Educational Forum – The Ed Forum is held annually at a different location in the US and features presentations directed specifically to patients and caregivers by medical professionals who specialize in the study of WM. The Ed Forum also offers breakout discussion groups on important topics and an "Ask the Doctor" question and answer session. The Ed Forum is a valuable opportunity for WM patients and caregivers to network with each other. Slide presentations and selected videos from each year's Ed Forum are available on our website. Additional information about the Ed Forum can be found on our website at <a href="https://www.iwmf.com/news-and-events/iwmf-educational-forum">www.iwmf.com/news-and-events/iwmf-educational-forum</a>

International Doctor-Patient Forum – This educational forum is held biennially in different parts of the world. It provides the opportunity for global patients to be updated on the most current WM research and treatment options by leading WM physicians/researchers who attend the International Workshops on WM. Presentations and videos from the most recent forum can be found at <a href="https://www.iwmf.com/library/media-library/iwwm-international-doctor-patient-forum">www.iwmf.com/library/media-library/iwwm-international-doctor-patient-forum</a>

**IWMF Website** (<a href="www.iwmf.com">www.iwmf.com</a>) — Our website provides education and information about the services and support that our organization provides, including a calendar of Support Group meetings and other events, a list of physicians who are knowledgeable about WM and available to offer second opinions, the ability to download many of our publications, details about our annual Educational Forum, videos from previous Educational Forums, webinars that are specific to WM, and information about our Research program. Our website is available in over 100 languages.

**IWMF-Connect and Other Internet Forums** – IWMF-Connect is an Internet-based discussion group in English about every aspect of WM. Information about how to join IWMF-Connect and other Internet-based WM discussion groups is available on our website at <a href="https://www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums">www.iwmf.com/get-support/iwmf-connect-and-online-discussion-forums</a>. Some IWMF International Affiliates also have Internet based forum in their native language and these can be found on the same webpage.

**Support Group Network and International Affiliates** –IWMF Support Group Leaders are WM patients or caregivers who are dedicated to providing information and emotional support for WM patients and their families worldwide through meetings and other activities. An educational workshop for Support Group Leaders is provided each year just prior to the annual Ed Forum. The list of current US and International Support Groups can be found on our website at <a href="https://www.iwmf.com/get-support/us-and-international-support-groups">www.iwmf.com/get-support/us-and-international-support-groups</a>.

The *IWMF Torch* – This quarterly magazine for our community includes articles about current medical research, clinical trials, and medical conferences of interest to WMers, as well as personal stories, tips on healthy living, and news about Support Group activities and IWMF events. *IWMF Torch* issues can be found on our website at <a href="www.iwmf.com/library/iwmf-torch">www.iwmf.com/library/iwmf-torch</a>.

**LIFELINE** – This service consists of IWMF volunteer peer mentors who answer questions about their first-hand experience with treatments for WM and other specific topics. A current list of LIFELINE topics, volunteers and their contact information can be found on our website at <a href="www.iwmf.com/get-support/lifeline-and-one-one-support">www.iwmf.com/get-support/lifeline-and-one-one-support</a>. Some IWMF International Affiliates also have a LIFELINE service which can be found on the same webpage.

**NEWS Alerts** – These are emails on topics about WM and the IWMF sent to our community.

**Booklets, Pamphlets, and Fact Sheets** – All of our publications are downloadable and available on our website at <a href="https://www.iwmf.com/library/iwmf-and-affiliate-publications">www.iwmf.com/library/iwmf-and-affiliate-publications</a>. Many are translated in languages other than English.

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## **BOOKLETS, PAMPHLETS, AND FACT SHEETS**

Waldenstrom's Macroglobulinemia – Frequently Asked Questions – This booklet answers frequently asked questions about Waldenstrom's macroglobulinemia in a very readable format for those who may not have a strong background in biology. It presents an overview of Waldenstrom's macroglobulinemia and is written especially for the newly diagnosed (available for downloading in English, French, German, Italian, Norwegian, Polish, Portuguese, Spanish, and Simplified and Traditional Chinese; in print in English). Revised 2019

Waldenstrom's Macroglobulinemia – Questions and Answers – This booklet is designed to provide detailed answers to questions about Waldenstrom's macroglobulinemia, including a full glossary of terms (available for downloading in English, French, Italian, Spanish, and Simplified and Traditional Chinese; in print in English). Revised 2017

Waldenstrom's Macroglobulinemia – Basic Immunology – This booklet is a comprehensive review of immunology is it relates to WM, including the cells involved, cytokines, immunoglobulins, and the genetics of immunology (available for downloading in English, French, Italian, Spanish, and Simplified and Traditional Chinese; in print in English). Revised 2018

Waldenstrom's Macroglobulinemia – Medical Tests – This booklet is a ready reference of medical tests used for the diagnosis and monitoring of disease status in WM patients (available for downloading in English, French, German, Italian, Polish, Portuguese, Norwegian, Spanish, and Simplified and Traditional Chinese; in print in English). Revised 2020

*Waldenstrom's Macroglobulinemia – Glossary and Abbreviations* – This is a list of medical terms and definitions pertaining to WM (available for downloading in English, French, Italian, and Traditional Chinese). Revised 2020.

**Treatment Options Guides** – This is a series of five pamphlets that discuss current treatment options and guidelines established by the Consensus Panels of the International Workshops on WM and by the National Comprehensive Cancer Network (NCCN) (available for downloading in English, French, German, Italian, Spanish, Simplified Chinese, and Traditional Chinese; in print in English). 2016, Revised 2019. The five Guides are:

Alkylating Agents & Nucleoside Analogs Corticosteroids & Immunomodulators Monoclonal Antibodies Proteasome Inhibitors Targeted Therapies/Pathway Inhibitors

**About WM Fact Sheets and Treatment Fact Sheets** – These are handy outlines of useful information about WM and certain treatments for it, including acalabrutinib, bendamustine, bortezomib (Velcade), human intravenous immunoglobulin (IVIG) therapy, ibrutinib (Imbruvica), plasmapheresis, Rituxan, stem cell transplantation, Venetoclax, and Zanubrutinib (available for downloading in English, French, German, Italian, Norwegian, Spanish, Simplified Chinese, and Traditional Chinese). Revised 2013, 2014, 2015, 2018, 2019, 2020

NOTE: All downloadable publications are available on our website at <a href="www.iwmf.com/library/iwmf-and-affiliate-publications">www.iwmf.com/library/iwmf-and-affiliate-publications</a>.