



IWMF Giving Guide

A guide to the many options for giving to the IWMF

The IWMF is a nonprofit organization with a volunteer Board of Trustees and many member volunteers who help with our various projects. All share the same mission – to support both new and established WM patients, their families and their friends, by providing educational and support services.

The IWMF also spends significant time and money exploring and funding WM related research. To help us carry out the many support services offered we have a limited staff at our office in Sarasota, Florida, to assist members in a variety of ways, to keep our records, and to ensure that our materials are printed and mailed to you. Members receive the Foundation's quarterly newsletter, the *Torch*, and other electronic bulletins of special significance in reporting new information and events, including special WM-specific programs such as our popular annual Educational Forum.

Below is a more detailed list of our services:

- *Local Support Groups* where people with WM and their families and friends meet to share information and to experience group support and friendship. There are 40 groups across the US with 6 more in Canada, expanding groups in Australia, Belgium, Denmark, Finland, France, Germany, Greece, India, Ireland, Israel, Japan, the Netherlands, New Zealand, and the United Kingdom.
- The *Educational Forum* that annually brings together leading WM specialists and researchers to inform patients of the latest developments and answer their questions.
- The *Torch*, our quarterly newsletter, filled with the most recent information about WM.
- The *IWMF Lifeline*, a contact listing for telephone and e-mail, is arranged by topic, and IWMF volunteers experienced in a particular topic will talk with callers on a one-to-one basis about their first hand experience and respond to questions.
- The *IWMF Website*, www.iwmf.com, a treasure trove of information.
- *Free publications* directed to you, your doctor, and your caregivers. Our publication list is regularly updated and expanded. See the website for a complete list.
- *IWMF-Talk*, an Internet e-mail list made available so that patients can communicate with each other about every aspect of WM and with experienced WMers who have been through a great deal and survived.
- The *Patient Database* is a registry, currently under preparation, which will contain the active medical histories of participating WM patients. Upon completion, all members will be encouraged to register.
- *DVDs* of presentations about the various aspects and outcomes of standard and emerging treatments for WM patients. The speakers are renowned scientists and clinicians from academia and cancer research centers.

Your Worldwide Advocate

WM is a rare disease that primarily affects us in later life. As such, it is not a “glamorous” disease because only rarely is it severely debilitating at the outset. WM does not usually attack those in their younger years. And WM does not gain the attention of those seeking to help cancer patients in general. Yet indirectly it greatly impacts the lives of caregivers, friends, family, and loved ones of all ages as they deal with the enormity of a person they love struggling with a rare disease that is incurable. Any assistance to that patient is also of tremendous assistance to those caregivers in easing their burden with the knowledge that there is viable long-term treatment for the future and hope for a cure.

The reality today is that all of the programs and services of the IWMMF are funded primarily by contributions from members, caregivers, friends, and family and that we are always struggling to finance an expanding number of offerings for our patients and their physicians. For the most part, we do not charge for products and do not have membership dues. We are here to provide a service and, if we do well, our members will continue to be generous in their contributions. Please consider giving what you can to any of our membership or research programs.

Two Ways You Can Give

There are two ways of giving – to the Member Services Fund and to the WM Research Fund. Both are very important but serve different purposes. We are careful with your contributions. Less than 14% of your donations to Member Services goes for administrative expenses. For the Research Fund, 100% of our income is used for scientific medical research.

The **Member Services Fund** supports the cost of providing such services as the printing and mailing of all our publications and the operating expenses related to the services itemized above. Also included are the costs of four face-to-face meetings each year by the Board of Trustees and multiple audio and video conference calls used by the Board, committees, and support groups. There are seven personalized levels of giving to the Member Services Fund that cover all levels of affordability (see the Gifts for Member Services under the Giving menus on our web page or Addendum A at the end of this document). The IWMMF offers regular giving options that enable you to choose monthly giving from your credit card or checking account or monthly, quarterly or annual giving for the designated period of your personal pledge up to 5 years. The suggested amount for monthly giving is a minimum of \$25. Note that Member Services Fund gifts may be given in honor of or in tribute to a specific individual, group, or organization. An option for corporation matching is also available.

The **Research Fund** is utilized exclusively for research. Research proposals received by the Vice President for Research are reviewed by the IWMMF Scientific Advisory Committee which is made up of outstanding members of the international WM scientific and medical community. Upon approval by the Scientific Advisory Committee, proposals are next reviewed by the IWMMF Research Committee, made up of Trustees and member volunteers with scientific backgrounds. Following the review process, recommendations are made to the full Board of Trustees to decide which projects are to be funded. The Research Fund enables you to give any amount and specify your gift in a variety of ways. Here is a list of the options designated for the Research Fund:

Eight Unique Gift Opportunities for the Research Fund:

Unrestricted Gifts for Research

Your gift in this category will be used only for WM research and may optionally be designated in tribute to or in memory of a person or persons of your choice. The 'in tribute' gift is for those who wish to send a gift to the IWWMF to acknowledge a friend, family member, colleague, or other person associated with an upcoming special occasion such as a wedding, birthday, anniversary, holiday, etc. The 'in memory' gift is to serve you and your loved ones during difficult times as accompaniment to a personalized condolence or *in memoriam* gift. Donors who have made gifts in honor or in memory, as well as the name(s) of the person(s) honored or commemorated, are listed in the *Torch*. Donors may also designate who is to be informed of the tribute or memorial gift. A personal note may be included as well.

The Incentive Fund

The Incentive Fund is designed to encourage participation from a broader constituency by doubling the dollars given. We were able to start this "double your dollar" program because of a \$100,000 establishment gift from one Trustee and several other generous donors. But we need more "philanthropic investors" to help seed the fund as we strive to complete a successful campaign.

If you accept the challenge and have an interest in giving \$25,000 or more to continue to "seed" the project — or in making a gift to the Incentive Fund below \$25,000 — please complete the online Research Giving and Pledge Form at IWWMF.COM and help us achieve success through this double-dollar project!

Fellowship Stipends

The "5-in-5" campaign also enables the Board to create a fund to support travel and educational expenses for M.D. and Ph.D. candidates (or post M.D. and Ph.D. professionals) from all over the world to study or work with established leaders in the field at sites such as the Mayo Clinic, Harvard University, and elsewhere. If you have an interest, please complete the online Research Giving and Pledge form found at IWWMF.COM.

[Recommended funding range: \\$5,000 and above.](#)

Naming Opportunities for Foundations, Companies and Organizations

Foundations and companies and organizations may wish to focus their resources on specific scientific and/or medical research projects. This kind of philanthropic investment justifies naming the project after the leader of the company, foundation, or organization in return for its gift or grant. If your organization has such an interest, please complete the online Research Giving and Pledge Form at IWWMF.COM, or contact Carl Harrington at 215.348.5656.

[Recommended funding range: \\$10,000 or above.](#)

Dr. Robert A. Kyle & Charlene M. Kyle Endowment Fund



In honor of Dr. Robert A. Kyle and Mrs. Charlene M. Kyle the first ever endowment program for the IWMF was established in 2009. The goal of this very important project is to raise one million dollars. The annual interest earned on the Kyle Endowment Fund will be used to sponsor research initiatives.

Everyone in our WM community knows Bob Kyle. Bob is a presenter at every IWMF Educational Forum, and he is featured in many issues of the *Torch*. He travels from one end of the globe to the other presenting lectures on WM and related cancers. From small support group meetings in church halls in Minnesota to the Stockholm research workshop, he enlightens both the newest patients as well as the veteran medical researchers on subjects of interest. He has received too many national and international awards to list here, and these from the most prominent sources in the field of cancer. In the WM world, it is safe to say that he is known as the "godfather of WM," having mentored many doctors who are now involved in WM research and seeing WM patients.

Bob Kyle was a friend of Dr. Jan Waldenström, who discovered our disease. He is also a friend to Dr. Waldenström's son, Dr. Anders Waldenström. Dr. Kyle is a special advisor and friend to the IWMF Board of Trustees. He is a charter member of the IWMF Scientific Advisory Committee and has been the Chair of that committee for over five years.

Dr. Kyle has not only treated many WM patients over the years but is also a pioneer researcher in WM. We owe Bob Kyle our highest respect and appreciation for his continued interest in our disease.

As a tribute to his outstanding contributions to the IWMF and all of its membership, the Board of Trustees of the International Waldenström's Macroglobulinemia Foundation has established the Dr. Robert A. Kyle and Mrs. Charlene M. Kyle Endowment Fund—the *first* endowment fund of the IWMF. The annual income from this fund will be used for activities, strategies, and programs associated with the IWMF Research Fund as determined by the IWMF Board and in accordance with special guidelines.

Our goal is to raise one million dollars. The IWMF membership – patients, caregivers, medical personnel—all are encouraged to contribute as we strive to reach our one million dollar objective.

To facilitate your gift response process, please complete appropriate sections in the Research Giving and Pledge Form or for an estate gift, complete the Ben Rude Heritage Society Enrollment Form with your planned gift intention. Both are downloadable at IWMF.COM.

Naming Opportunities for Individuals

Projects or programs in tribute for a person or in memory of a patient are provided through the tribute and memorial cards mentioned above. Such contributions are usually made at a comparatively lower level of giving. The 5-in-5 campaign provides a naming opportunity for individuals (patients, doctors, past and current Board members, caregivers, etc.) at a higher level. Endowment options may be considered in this area. See the Dr. Kyle Fund for an example. If you have an interest, please complete the online Research Giving and Pledge Form at IWMF.COM.

Recommended funding range: \$50,000-\$1,000,000

Ways of Giving through Estate Planning and Planned Giving

There are different ways to experience the “joys of giving” through planned or deferred giving. In general, the “ways of giving” fall under three general categories: bequests, life income, and other special planned giving vehicles.

Estate Gifts

You can use your will or bequest, a codicil to your will, or alternatives to a will such as your IRA or pension plan, to leave a permanent legacy for the IWWMF.

Some Definitions: *Bequests are made in wills, codicils, living trusts, and other estate plans whereby money, property, or both are given to a nonprofit organization. A codicil is a written change or amendment to a will. A bequest or codicil could take the form of a fixed amount or a percentage of your estate plan.*

Examples: “I give, devise and bequeath to International Waldenstrom’s Macroglobulinemia Foundation, a nonprofit foundation located in Sarasota, Florida, [dollar amount or percentage] to be used for its _____ purposes. I further direct that interest or other income which may be earned by said bequest shall be paid to IWWMF from the date of my decease until paid.”

Life Income Gifts

Life income gifts offer the donor income for life, or for a specified term of years, in return for making an irrevocable gift to IWWMF.

Example: *A Charitable Remainder Trust* provides income to the donor’s beneficiaries and the remainder to IWWMF. Payments are determined annually and depend on the value of the trust assets as recalculated yearly.

Example: *A Gift Annuity* provides the donor with a contractual promise of fixed income each year. The payout rate depends upon the age of each beneficiary at the time the gift is made and when the payments begin. Payments can be deferred for several years.

Other Planned Gifts

Here are three examples of other deferred gifts to IWWMF:

Example: *A Life Estate* provides IWWMF with a gift of residence or farm while allowing the donor the right to continue to live there for the remainder of his or her life.

Example: *A Charitable Lead Trust* provides IWWMF with income for a term of years and leaves the remainder to the heirs of the benefactor.

Example: *Life Insurance* designations allow a charity to receive benefits upon the death of the insured.

Be sure to see your attorney or tax adviser as you put your plans on paper. [Go to the Gifts for Research page at IWWMF.COM](#) for the Ben Rude Heritage Society information and enrollment form, or for additional information call Dave Benson at 952.837.9980

The Ben Rude Heritage Society



The Ben Rude Heritage Society is named in recognition of the second president of the International Waldenström's Macroglobulinemia Foundation. Ben Rude served as president for over four years before he passed on in January 2005, but his legacy carries on thanks to the leadership demonstrated by the members of this society. Join other members of this honorary society and help make Ben's dream of a cure for WM come true. Ben's spouse, Laurie Rude, serves as the founding Honorary Chairperson of the Ben Rude Heritage Society.

This society was established by the Board of Trustees in 2008 and the founding members were recognized during the Ed Forum at Los Angeles in that year. Each year the Trustees are pleased to honor new members of this Society who have followed Ben's legacy of leadership with various types of deferred gifts to the IWWMF, such as a bequest, a gift annuity, a trust arrangement, an insurance policy, or a similar planned gift.

A legacy gift is the ultimate expression of support for IWWMF. Through your planned estate gift and your participation in the Ben Rude Heritage Society you can touch the lives of others as we strive to find the cause and a cure for WM. Nearly one million dollars have been pledged or received after only two years. Placing your treasure in the care of our Foundation will insure benefits for others long into the future. As Ben shared often, "A person's life is measured by the effort made for the benefit of others."

Summary

You might say the Member Services Fund is the life blood of the IWWMF and the Research Fund is directed at finding a cure or treatment options that increase life expectancy and our quality of life. Please select the fund of your choice by either going to the Give Now button on our home page or the Giving menu at the left of each web page.

WM is such a rare disease - it affects only a few out of every one million people - that it is considered an "orphan" disease. And an orphan disease receives little government, agency, or institutional attention. It is appropriate, when millions are dying from breast, colon, prostate, and other cancers, that the greatest attention is focused on the major cancer killers. But if we want things to change in regard to our healing and treatment opportunities, we are going to have to do it ourselves. This is the reason for the founding and continued existence of the IWWMF.

We are accomplishing a lot with a little, but imagine how much more we could do if we had a lot! Don't wait for someone else to do it for you. **The IWWMF thanks you as you seriously consider joining, volunteering, and giving as soon as you are able!**

**If you would like to make a gift, please visit our website: iwmf.com,
mail an envelope from the *Torch*, or contact the IWWMF Office:**

3932D Swift Road, Sarasota, FL 34231

Tel: (941) 927-4963

Addendum A

Giving Circle Descriptions for the Member Services Fund

WMer (\$1-\$99 annually)

All giving has to start somewhere. The IWMF is grateful for all gifts no matter what the size. This is the first level to join the WM Family.

Circle of Friends (\$100-\$299 annually)

Join the WM Circle of Friends and help support the distribution of information about WM to all patients, members or not.

Support Group Circle (\$300-\$499 annually)

A gift at this level honors and encourages the IWMF support groups whose members and their leaders reach out to one another to share information and experiences. Note that this level is the lowest level that offers a monthly giving option.

WM Family Circle (\$500-\$999 annually)

With your gift at this level you honor the extended family of patients, families, friends, physicians and researchers. Note that this level also offers a monthly giving option.

Caregiver Circle (\$1000-\$2499 annually)

This level of giving honors our caregivers, our doctors, and our nurses for their personal care and guidance. They educate so many of us at our Educational Forums and local support group meetings while we walk the WM patient path. This level also offers a monthly giving option.

President's Circle (\$2500-\$4999 annually)

The IWMF is where it is today due to the dedicated efforts of past and current IWMF presidents Arnie Smokler, Ben Rude and Judith May. We encourage you to join at this level and honor these dedicated presidents for their hard work and commitment. Note that this level also offers a monthly giving option.

Trustee Circle (\$5000 or greater annually)

At this level of giving you are honoring the volunteer Board of Trustees who together with volunteers provide the services and support you receive for your membership. Giving at this level makes a significant statement to the leadership that you are behind them in our mission to improve the quality of life of Waldenstrom patients and to find a cure for our persistent orphan disease. The Trustees very much appreciate the priority that you give our organization on your list of many worthy causes. Please validate the vision, goals and legacy of the IWMF by joining the Trustee Circle. Note that this level also offers a monthly giving option as well as naming opportunities shown below.

Trustee Circle Naming Opportunities:

The Membership Services Fund addresses operating costs, expenses incurred to provide support and information to Waldenstrom's patients, caregivers, families, medical professionals, and friends. Basic expenses include daily mailing costs and staff wages.

Major gifts in support of such IWMF services as national educational forums, booklets about the treatment and management of Waldenstrom's macroglobulinemia, informational brochures—or even sponsoring an issue of the IWMF's newsletter—can be gratefully acknowledged in the *Torch*. At the discretion of the benefactor, his or her brief biography will be printed in the *Torch* as well. Donors of gifts for other publications or for educational events can be acknowledged in the relevant publication or announced at the event sponsored by their gift.

To pursue a naming opportunity, complete the Member Services giving form at the WM Trustee Circle Level and call Don Brown at 630-323-5894 for additional information.