



# IWMF

International Waldenstrom's  
Macroglobulinemia Foundation

## Special Bulletin - Treon Makes Significant WM Research Progress!

### Giving Links

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Direct link for Gifts to  
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membership and make  
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NOTE that the above  
link provides a form to  
print and send in by  
**POSTAL MAIL**.

Steven Treon,  
MD, PhD



Physician and  
IWMF Research  
Partner

December 2011

Dear Steffen,

Exciting news! Researchers at Dana-Farber Cancer Institute have identified the first gene mutation that may characterize the vast majority of Waldenstrom's macroglobulinemia (WM) cases. More specifically, research led by Dr. Steven Treon and Zachary Hunter, and funded in part by the IWMF, discovered:

- A single gene mutation in 90% of Waldenstrom patients whose DNA was sequenced.
- This mutation will help to distinguish WM from other types of lymphoma, including multiple myeloma and MGUS.
- This mutation produces an abnormal protein which activates the NF-kB pathway, essential for the growth and survival of WM cells.
- When researchers shut down this pathway with drugs that blocked the abnormal protein, the tumor cells died. Healthy cells did not.
- This suggests that new, effective treatments that target WM tumor cells directly are on the horizon.

This doesn't yet mean a cure, but we are one step closer than ever.

Dr. Treon announced the new findings on December 12th at the American Society of Hematology's (ASH) annual meeting in San Diego. Those of you who were at the Minneapolis Ed Forum in May heard a preview of these findings. A summary of Dr. Treon's presentation at the Ed Forum can be found on page 19 of the Ed Forum Review: 2011 or on our website at [this website link](#). Dr. Treon has also agreed to write a special article for the April 2012 issue of the *Torch*. A copy of the Dana-Farber press release of the ASH presentation is on our website at [this website link](#).

Dr. Robert Kyle  
at 2011 Education  
Forum



**IWMF Board Member and SAC Chairman; The IWMF SAC (Scientific Advisory Committee) meets periodically to direct IWMF research dollars to relevant projects that advance our knowledge of WM biology and improve treatment options.**

*DVD set still available of our 2011 Education Forum*

**Link to order:  
[DVD Website Link](#)**

*Happy and Healthy 2012!*



The importance of this discovery is enormous. Quoting from the Dana-Farber press release, "Drugs that block the abnormal protein or other proteins in the NF-kB pathway could, theoretically, short-circuit the disease process in many patients. Some of these drugs already exist, having been developed for other conditions. Treon and his colleagues are currently working to develop others and are testing them in experimental models."

We should all take pride in IWMF's investment in this study and in our other research studies, where other pathways and proteins are being discovered that will eventually lead to controlling the growth and death of WM cells. Answers do not come quickly, as medical research is a slow and methodical process and sometimes leads to dead ends, which are also very important as they tell researchers not to look further in those directions. However, with this seminal research by Dr. Steven Treon we are definitely moving ahead.

There is still much work to be done toward improving treatments and searching for a cure, not only in genetics, but in the study of the environment where WM cells live and what impacts their survival and growth. We know from your past generosity that all patients want to be a part of the search for better treatments and a cure, and a great way to do that is to make a **special year-end gift** to the IWMF. Please [click here](#) to donate to IWMF **Research Fund** or [click here](#) to donate to IWMF **Members Services Fund** which includes covering the administration costs of our research grants. Both IWMF funds are very important.

Why give to the IWMF now?

- These crucial genome findings will increase the demand for additional funding for a broad variety of IWMF-funded research to follow up on these results. We need to be in a position to fund the critical research that will incorporate and build upon the latest findings.
- In addition, we expect that the genome findings will lead to additional research applications for new drugs or new applications of drugs. We need to be ready to fund the best of these as well as other new directions inspired by this discovery.

All IWMF research projects are reviewed by our prestigious Scientific Advisory Committee (SAC), chaired by Dr. Robert Kyle. This committee consists of the best minds in the world of WM research. Collectively, this group chooses the most promising and most strategic research for the IWMF to invest in. It also provides comments and tweaks the direction of the research to ensure it incorporates all of the best current thinking. The result is that the IWMF funds the most critical

research on a global basis as recommended by the best WM researchers in the world. To see a list of the members of our SAC, visit [this website link](#).

Let's put your research dollars to work where they are most needed. Let's build on the current findings and accelerate our search for a cure! The next 5 years will be critical. We need your help to have the resources ready to support the best research ideas wherever they are in the world.

Happy Holidays to everyone! Thanks for your continued support for the IWMF and for the critical research that still needs to be done.

The Fundraising Team  
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