



# 2016 IWMF Educational Forum

## Imagine a Cure: Pathways to Progress

Carl Harrington, IWMF President



# Pathways to Progress

A photograph of a dirt path in a forest. The path starts from the bottom center and splits into two paths that lead into the distance. The forest is dense with green trees and undergrowth. The text "Pathways to Progress" is overlaid in large, bold, orange letters across the middle of the image.



# Where have we been?

What is WM?

Where can I  
learn more  
about this  
disease?

Where can  
I find help?

What kind of  
treatments  
should I take?

How long do I have  
to live????

- IWWMF started in 1994 with 30 people
- Now over 8,000 in over 70 countries

# You are not alone!

- *IWMF Support Groups*: Over 55 worldwide
- *IWMF-Talk*: Over 1900 members
- *IWMF Lifeline*: About 50 volunteers on 40 topics
- *IWMF NEWS*: Topline news
- *IWMF Torch*: Keeping you up-to-date on everything WM
- *IWMF website*: Everything you need to know about WM

# You are *definitely* not alone!

- *IWMF publications*: Free & downloadable; available in multiple languages
- *IWMF Physicians Directory*: Over 72 doctors worldwide
- *IWMF Facebook*: 1400 public members; 1200 private members
- *IWMF YouTube video channel*: About 50 videos
- **IWMF Waldenfriends!**

# Where do we go?



# We often face tough choices



# Where have we been?

- Invested over \$8.3 million in WM Research.
  - All funded by YOU!
- Discovery of MYD88 and CXCR4 genetic mutations
  - 90-95% of WMers have MYD88
  - 30-40% of WMers have CXCR4
  - Vs. other diseases
- FDA approval of Ibrutinib in January 29th, 2015
  - 1<sup>st</sup> ever drug for our orphan disease



It hasn't always been easy



*"We should make it past the rocks by nightfall, provided our luck holds."*

# IWMF-LLS Strategic Research Roadmap

- Alliance with LLS (Leukemia & Lymphoma Society)



# May 2015 Roadmap meeting

- Identified 4 key areas for further research
  - **Bone marrow/Tumor Microenvironment (Dr. Ansell)**
    - How can we change the environment or “neighborhood” WM cells live in so they can no longer thrive?
  - **Immunotherapy (Dr. Stadtmauer)**
    - WM cells often “hide’ in their environment & aren’t recognized by our immune system. How can we use our own immune system to fight WM?
  - **‘Omics (Dr. Hunter & Dr. Melnick)**
    - How can we use genomics and epigenomics to to understand and leverage WM mutations?
  - **Cell signaling (Dr. Treon)**
    - What pathways do WM cells use to communicate and how can we interfere with these pathways to prevent communication?

# Request for Proposals

- Developed jointly with LLS
- Issued November, 2015
- Received 18 high-quality proposals from around the globe





# Project Moonshot

- National effort to end cancer as we know it.  
Chaired by Vice President Joe Biden
  - Cancer doesn't discriminate
  - We are at an inflection point
- “Cancer is now known to be hundreds of diseases, each with unique features, driving forces, and vulnerabilities”
  - Immunotherapy
  - Attacking multiple pathways
- Goals:
  - Make 10 years of progress in 5
  - Cure some cancers
  - Make others into chronic diseases





abc NEWS

# Project Moonshot Focus

- Breaking down barriers and enhancing **cooperation**
- \$\$\$\$\$\$\$\$\$\$\$\$\$\$

A low-angle, close-up photograph of several hands of different skin tones stacked together in a circular formation, creating a sense of unity and teamwork. The hands are silhouetted against a bright, overexposed background, with some fingers pointing towards the center. A few accessories are visible, such as a metal bracelet on the top left and a ring on a finger in the lower left.

**Cooperation is what we do  
in WM**



# We are not alone!

- Partnership with LLS on Research Roadmap
- Partnerships with LRF; CancerCare; Lymphoma Coalition; Lymphoma Canada: NORD; EWMn; Hematon; Association of Oncology Social Workers
- Partnerships with Research & Treatment Centers:
  - Our speakers this weekend: DFCI; Mayo Clinic; University of Pennsylvania; Colorado Blood Cancer Institute; Weill Cornell; Brigham's Women's & Children's Hospital; University of Alabama @ Birmingham; New England College of Optometry
  - Our SAC members: Mayo; DFCI; MD-Anderson Cancer Center; Mount Sinai Hospital, Institute for Myeloma & Bone Cancer Research, West Hollywood, California; Alexandra Hospital, Athens, Greece; Columbia University; Karolinska Institute, Stockholm, Sweden; Hôpital Pitié Salpêtrière, Paris, France; St. James's Institute of Oncology, Leeds, United Kingdom
  - All the doctors on our Directory of WM Physicians: **72**
  - Attendees at our Strategic Research Roadmap Meetings
- Partnerships with the pharmaceutical industry

# 2016 IWMMF-LLS Strategic Research Roadmap Meeting May 20-21, 2016

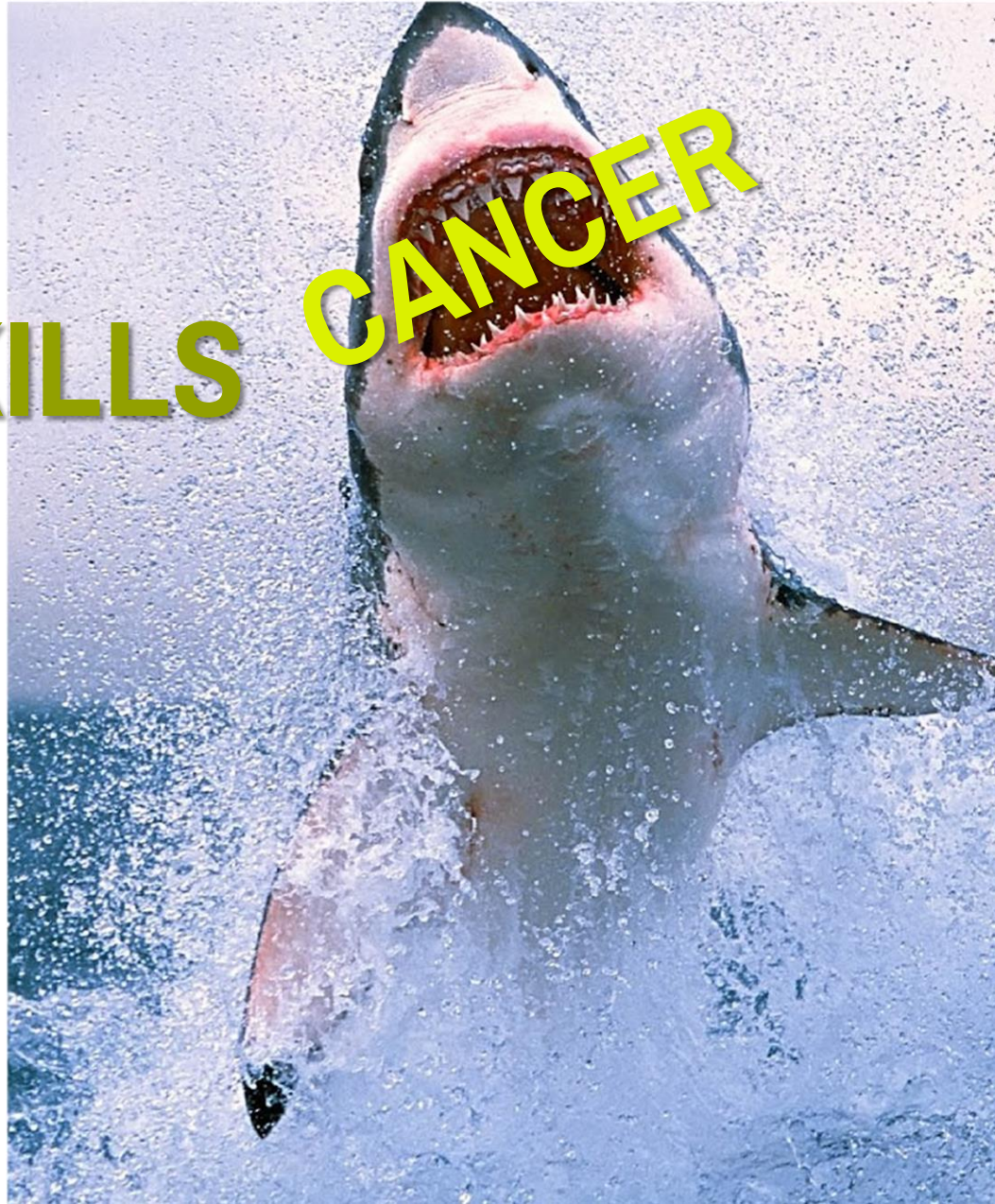


**Remember this!**

**RESEARCH**

**KILLS**

**CANCER**







**What pathway do we choose?**



# As many pathways as we can afford!

- What do we need?

- \$\$\$\$\$\$\$\$\$\$

- People

# Help us reach the moon!

