



Welcome to the 2015 IWMF
Educational Forum
Imagine a Cure: Parade of Hope



Newly Diagnosed

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And
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May 2, 2015



Newly Diagnosed

- A cancer diagnosis is very scary
 - Description of WM is “incurable cancer”
 - Published prognosis is 5-7 years and is very outdated
 - Some patients do not need treatment, hard concept to understand with cancer (Watch and wait concept)
- Time of emotional stress (lack of sleep, exhaustion and concern for family and friends)
- Time of confusion
- Time of doubt



Steps to Take

1. Come to terms with your diagnosis
2. Decide who you're going to tell about your diagnosis
3. Get a second opinion at a center of excellence
4. Find a patient group that focuses on your disease



Steps to Take (continued)

5. Educate yourself
6. Find support for yourself and your caregiver(s)
7. Consider a clinical trial if you need treatment



Means of Education

- IWMF Information Packet
 - Available from the IWMF office in Sarasota, FL by calling (941) 927-4963 EST or at www.iwmf.com
 - This newly diagnosed information package has a wealth of information which will be a start in the education journey
- Attend a local support group that is organized by the IWMF
- Attend the annual Patient Education Forum!



Means of Education (cont.)

- Utilize the IWMF website (www.iwmf.com)
- Join and read the IWMF talk-list
 - Active participation or just lurking
 - IWMF website has instructions on how to join
- Read the Torch Newsletter
 - Comes out quarterly and can be sent electronically or through the mail



Personal history

- Carl and Pete's personal journey with Waldenstrom's



Tips for Managing your WM

- Keep detailed records of your treatments and the dates when they are given
 - You will be able to see how you respond to treatments and to see trends, which are so important in WM
- Keep copies of all your lab results (I put my results in an Excel spreadsheet)
 - My oncologist likes to be able to see my records over a long time period
- Before you have visits with your oncologist prepare ahead by writing down any questions you might have
 - If possible, **have someone with you** for your doctor visits



Tips for Managing your WM

- Partner with your doctors, nurses and office staff
 - Consider consultation with a WM specialist if your local oncologist has not had much experience treating WM
- Stay current in your knowledge of new therapies
- Consider participating in clinical trials
 - www.clinicaltrials.gov



Tips for Managing your WM

- Stay Hopeful: The field is evolving quickly with new discoveries and techniques to solve this mystery
 - Many new drugs are being tested
 - Genome sequencing is happening now and affords great promise

Questions???

