

# Beacon of Hope

## In Honor of Jack Whelan

Diagnosed with a rare, not-yet-curable blood cancer, Jack Whelan is a passionate booster for research, clinical trials and safer, more effective cancer therapeutics.

When diagnosed with a rare, lymphoplasmacytic lymphoma called Waldenstrom's Macroglobulinemia in April 2007, much of the on-line content and literature indicated a roughly five-year survival for symptomatic patients that began treatment for this cancer that affects roughly 1200 people each year. As most of the therapies are "borrowed" from other blood cancers and the historical outcome at that time was "not that exciting", Jack felt looking behind door number three, what's in research, what's in clinical trials was a prudent step forward. felt considering what we're learning about genetics and genomics betting on forward-looking science made more sense than the standard of care". It's unfortunate that only 3-5% of patients participate in clinical trials because they are never even asked to consider this option. We have to do a better job educating Primary

Care Physicians and encouraging major academic institutions to engage more effectively with local regional health care providers.

When you're told it's not curable, it's much like being told, you can't win at this game. I wanted to learn more to stay in the game as long as possible. It's no secret that we're making meaningful progress with new molecular level targeted therapies each year. So achieving even one year of progression free survival is a major leap forward. Jack believes patients should be actively involved in their care. Far too many patients take "the car wash approach" where you sit passively and ride through with little or no control. Jack wanted to learn about the biology of my cancer, the variety of treatment options and potential side effects and outcomes.

Jack was fortunate to find an oncologist, a principal investigator who had a keen interest in this very uncommon B-cell malignancy. Dr. Irene Ghobrial at Dana Farber Cancer Institute exhibited the best qualities of a physician that conducts research in the lab and compassionate care in the clinic. Jack and Dr. Ghobrial have been together in this partnership from the outset. She has encouraged me to be educated and engaged in Jack's cancer journey.

After retiring from his career as a Research Analyst covering tech stocks,



Jack made the transition to Research Advocacy. It's part of Jack's medicine to be a patient advocate, helping new patients diagnosed with this disease in connection with the Leukemia & Lymphoma Society and managing the New England Support Group for the International Waldenstrom's Macroglobulinemia Foundation. There are many opportunities for patients to serve as advocates. Jack is very active associate member with the American Association for Cancer Research (AACR), and a member of the American Society of Clinical Oncology (ASCO) and the Drug Information Association (DIA). As a Research Advocate, Jack is a strong proponent of rational funding for biomedical research, in particular funding for NIH at this critical time.

He is an effective patient's voice on behalf of biotech and life sciences industry encouraging a strong government and commercial partnership for the benefit of all patients. The opportunities for better outcomes and more cost-effective care have never been better. In Legislative Advocacy, Jack has been described as a powerful one-man band with a big drum leveraging the capabilities of larger professional advocacy organizations to help educate policy makers and lawmakers about the need to fix out-of-date assumptions concerning cancer care. Jack helped spearhead the Oral Chemotherapy Parity Bill and more recent Biosimilars Clarification Legislation in the Commonwealth of Massachusetts. He regularly participates in advocacy programs and face-to-face meetings with State and Federal lawmakers.

Using his communications and business skills as an IT Research Analyst, you can now find Jack frequently "on the road" speaking at a long list of US and European Life Sciences Conferences. I'm honored to be asked to speak to business-focused, life sciences audiences where I represent an uncommon, unique patient's voice normally not heard at most of these venues.

Jack recently completed his twelfth cycle (12 months) of twice-weekly chemotherapy infusions, part of clinical research and is happy to report meaningful progress as he hopes to move on to a novel agent in pill-form to manage his blood cancer. He and his wife and best caregiver ever, Jan celebrated their 45<sup>th</sup> wedding anniversary this year. They live in Andover, MA. They are the proud parents of three fabulous daughters, Laurie, Patti and Karen, three wonderful sons-in-law and now the proud grandparents of six grandkids, two sets of twins that include four girls and two boys.