



International Myeloma Foundation

The Myeloma Mobile

„Ahead of the Curve„

IN THEIR OWN WORDS



Robin and Michael Tuohy

≡ ROBIN TUOHY

Our own experience made us fully realize the value of a 'myeloma community.' Of course, the IMF already understood this. That is why they advise over 100 locally based myeloma support groups. But at the time, there wasn't one in our area.

In 2001, the IMF provided us with the resources, contacts, and encouragement to form a new group. To this day, about 20 of us meet every month to talk, to listen, and to share information and inspiration. On this mission I want to meet with other caregivers, who like me have a family member with myeloma living at home.

≡ MICHAEL TUOHY

Nearly seven years ago, I was 36 and happily living what I viewed as a typical American life: I was working full-time while my wife Robin stayed at home to raise our two young children. Allison was 7. Mikey was 2. Then, in September 2000, the severe back pain I was experiencing became debilitating. I could no longer bend down to play with my son and daughter, let alone dream of picking them up. Still, I never could have imagined how a visit to the doctor would end up changing all of our lives forever.

I was diagnosed with myeloma, a complex, and often misdiagnosed, bone marrow cancer that attacks and destroys bone. Robin and I knew nothing about this cancer, except for what the doctors told us that day: There is no known cause of myeloma, and there is no cure. We were told the average survival rate was five years.

I fear too many of you know what that moment feels like— being plunged into a scary, unknown world, doing the quick math and realizing that five years isn't nearly long enough. But there had to be a ray of hope.

Robin and I quickly found the IMF whose founding motto is "Knowledge Is Power." I wholeheartedly agree.



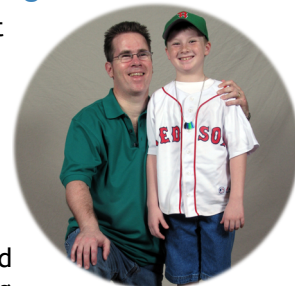
≡ ALLY TUOHY - age 14

On this trip I want adults to know it is better when they talk to us and share with us. We cope better when we know what is going on.

Sure this has changed my life, but I believe this experience has made me a better person. I am not superficial. I really know what's important in life.

≡ MIKEY TUOHY - age 9

Myeloma is scary, but my dad helps people to not be as scared. He is very brave.



Once Robin and I more fully understood what we were dealing with, it was time to make some decisions about my treatment. After initially stabilizing my myeloma, and shrinking my tumor, I had a stem cell transplant in September 2002. At first, everything was promising, but slowly the numbers began to increase. I began to face the reality that more treatment might be in my future. Then, in the summer of 2005, after 2 ½ years of remission, my myeloma was active again. What now?

Fortunately research into myeloma has achieved a small group of new drugs called the novel therapies - Thalomid, Velcade and Revlimid. They can be used in sequence, one after the other each time we come out of remission, and new studies show they can even be used in combinations for entirely new results. In my case the IMF helped me find a clinical trial for REVLIMID, at the time an experimental drug. It is an oral medication without the ravages of chemotherapy.

As I prepare to head out on our journey, I'm thrilled to report that I've now been in full remission since spring of 2006. I don't take a millisecond of it for granted.

The International Myeloma Foundation, headquartered in North Hollywood, California, is the oldest and largest myeloma organization, reaching more than 135,000 members in 113 countries worldwide. A 501 (c) 3 non-profit organization dedicated to improving the quality of life of myeloma patients and their families, the IMF focuses on four key areas: research, education, support and advocacy. To date, the IMF has conducted more than 120 educational seminars worldwide, maintains a world-renowned hotline, and operates Bank on a Cure®, a unique gene bank to advance myeloma research. The IMF was rated as the number one resource for patients in an independent survey by the Target Research Group. The IMF can be reached at (800) 452-CURE or www.myeloma.org.