

Boston Greeting

1 May 2009

3rd International Summit on Waldenstrom's Macroglobulinemia

How wonderful, and how exciting it is, to be here together, to join forces, to combat and conquer our common enemy, Waldenstrom's macroglobulinemia.

In the fall of 2005, when I participated in a clinical trial, I used to picture my drug exploding all the cancer cells. Tonight I'm honored to explode two longstanding myths about this disease, and also deliver two fabulous pieces of news. As you might guess, they're related.

So: Myth #1: Waldenstrom's macroglobulinemia is an orphan disease. Well, the disease may be considered an orphan, but the fabulous news is: We are not!

Look around—feel the buzz. Here we all are, 230 people diagnosed with this disease, who know it from the inside out. Plus 230 people who are our relatives and our friends, who know this disease through compassion and care. Plus 55 doctors and researchers, who make it their life's work to know this disease from the outside in. The way I do the math, for every four patients, we have one doctor or scientist devoted to improving our health and life. The way I do the math, for every one patient, we have one devoted companion. That's not an orphanage, it's a family.

For this family reunion, we come from every part of North America, from California and New York, from Florida and Maine, from Texas and Washington, and from Canada, too. For this family reunion, we come from as far away as Sweden, Italy, Greece, and Japan. Our initial bond may be sickness, but our shared commitment is health.

For his boundless devotion, patience, and care, I am grateful to my husband, Bill Zielinski. For his expansive science, encouragement, and care, I am grateful to my doctor, Dr. Steven Treon, and all of his Mighty Team. Because you were there for me, I'm able to be here for you.

Myth #2: Waldenstrom's macroglobulinemia is a rare, incurable lymphoma. As more and more people receive this diagnosis, Waldenstrom's becomes a tad less rare. As more and more clinicians and researchers zero in on its causes, they also zero in on its cures.

I have no doubt that the term "incurable" will soon be erased from this disease. I have no doubt that more and more of us will be cured and cancer-free.

Amid all the learning, sharing, and questioning of the next couple of days, I have no doubt that we'll all have even newer ideas, and we'll all make even more creative connections. With clinical observations and laboratory findings as the foundation, our hearts and minds, together here now, will accelerate the drive to a cure, or because this disease is clever, a range of cures.

I'd like to share with you three components of our project—the project to cure Waldenstrom's macroglobulinemia—that both anchored me and propelled me. I respectfully offer them for your consideration.

First, an informed, educated patient who asks many questions is his or her own best advocate, and the doctor's best ally. Well, we're all here, so we all agree on this one.

Second, the mind-body connection is a formidable force for healing and for health. Or, to quote my father, "The mind influences the chemistry of the body." Facing this or any cancer, our mental, emotional, and spiritual resources are powerful complements to our drugs. A calm mind and an optimistic attitude support our bodies in our quest for health. The holistic approach I pieced together included ancient Eastern healing techniques and meditation. Meditation can, of course, be considered a form of prayer.

Third, the need for, and the value of, clinical trials and biology-based treatments cannot be over-emphasized. For me, in a twelve week clinical trial, a synthetic monoclonal antibody eradicated Waldenstrom's macroglobulinemia. This is the type of result all of us want, for everyone with this lymphoma, and for everyone with any and every cancer. Let's be open to enrolling in clinical trials, and to asking for more of them.

I'm most grateful to each of you for your commitment to health. Together this weekend, we will make a difference.

Thank you for making the effort, and devoting your time and energy to be here.

L'Cha'im! To Life!