

Good Morning Ms. Chairman and the Committee Members,

For the record, my name is Mutsuko Holiman and I am a nurse. I live in Plaistow, New Hampshire with my husband and four children. I want to thank each one of you for your time. The opportunity you have given us to share our concerns means a lot to us.

In 1986, when my sister was diagnosed with Chronic Myelogenous Leukemia, I flew back to Japan to care for her. My experience as a RN here and knowledge I had gained from an oncologist had persuaded me to seek a bone marrow transplant as the only treatment that would give her hope of survival. It was at a time when there was limited availability of information or resources about unrelated bone marrow donation as a therapy for conditions like my sister's. Along with visionary physicians, patients and families and the researchers who studied HLA, I was able to start the movement to establish an unrelated donor registry. My advocacy and lobbying efforts and those of my sister eventually were successful and resulted in the first bone marrow donor registry in Japan, now called the Japan Marrow Donor Program.

My sister subsequently received her donor marrow from our mother who was a perfect match, a miracle that saved her life. I, her only sibling, was not a match and there was no registry any where in the world to even do the search. We have just celebrated the 19th year since her transplant. In those years, we have met and lost many friends who died without the hope to have a transplant, both in Japan and the US.

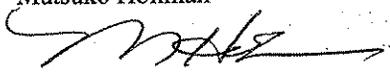
Since I returned to the United States 15 years ago, I jumped right into recruitment as I saw the same need to increase the awareness and the need for committed donors. I recently served six years as a board member for the National Marrow Donor Program where I have learned much of what I know today. Though I have focused on the minority needs and the advocacy for those underserved, I have closely worked with the Caucasian community as well, as I live in one. I decided that I was going to change the meaning of the term Minority in this cause so the need is differentiated clearly in my head. Minorities are the ones who possess HLAs(Human Leukocyte Antigens) that we cannot find the identical donors for. And they come in many colors, mostly, at this point Caucasians.

The NMDP is hard at work to help fund the drives organized by the recruiters and volunteers. Until we find that one magic pill to cure these blood related diseases, we must press on to recruit more people to get on the registry. Every year, we lose numbers of potential donors from the registry due to age limits, medical deferrals, and simply because we are not able to contact them. We depend solely on human good will and do not coerce them to be donors. For these reasons, though we boast 10 million potential donors registered World Wide (6 million from the NMDP); we are not yet able to find donors for thousands of patients.

I hope your recognition in this matter will encourage the insurance companies to come forward to work with us to find a solution to this challenging task. My contact information is listed in this paper. Please feel free to ask any questions anytime.

Thank you for the opportunity to share my testimony today.

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