

Written Testimony Regarding Transplant Discrimination HF1080

Senators:

My name is Jean Bender. I am the parent of an adult with multiple disabilities including Down Syndrome, autism, and quadraparesis. About two years ago, David began having irregular blood test results, indicating anemia that had no known origin. When it progressed to severely impact his quality of life because of the chronic low energy and fatigue, we were referred to a hemotologist/oncologist. This is what she said after greeting us, having never met us previously: "I've reviewed David's test results and our next step would be a bone marrow biopsy. Because David would not be a candidate for treatment of what we might find (alluding to leukemia requiring a potential bone marrow transplant), I'm not recommending the biopsy, but you may choose to pursue if you wish."

We did wish. David had the bone marrow biopsy, and leukemia was ruled out as a cause of the anemia. Had we not insisted on the biopsy, we would have watched our son rapidly decrease in strength and health until he died of **kidney failure**. Because after the bone marrow biopsy failed to find a definitive cause, other tests were done that indicated the anemia was caused by Chronic Kidney Disease. He was able to undergo a procedure that slowed the progression of CKD and improved his quality of life.

Had we listened to a doctor who made treatment assumptions on David's disability diagnoses and a few test results, we would not have had the necessary information to properly intervene to halt his rapid decline. Transplant decisions should only be made with all of the facts, including the individual and family perspectives on quality of life with and without treatment. As in our situation, specialists who recommend treatments at a 15-30 minute first appointment or by reviewing medical records are not the people who should make such serious decisions on transplant eligibility. The individual and family should be the people who make the decision because they know the most about a person's attitude towards treatment, pain tolerance, and quality of life expectations with or without treatment.

Please support this legislation.

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