

## I Hate Muscular Dystrophy: Loving a Child with a Life-Altering Disease

Written by Book Review by Kam Williams  
Friday, 02 September 2011 10:49

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*“This is a personal story of a family’s ability to love and support each other through the unexpected challenges of a life-transforming condition. It speaks of the strength and resolve of a mother who believes that life is to be lived and celebrated, despite any real or perceived limitations...*

*It gives us poignant glimpses into the initial disillusionment of a parent’s dream for her child, while at the same time, openly embracing all of the gifts that this experience has to offer... I*

*Hate Muscular Dystrophy*

*shows us that life can be beautiful even during periods of despair and pain. It helps us know that miracle and wonder of life is found... in simple moments of mystery and grace.”*

-- Excerpted from the Foreword by Dr. Julie vanPutten (pg. vii)

Unless your life has somehow been touched by Muscular Dystrophy (MD) directly, the only time you probably think about the disease is during the Labor Day Telethon hosted annually by Jerry Lewis since the mid-Sixties (up until the recent announcement that he’s being replaced as emcee next month). And while making a contribution to a worthy cause like “Jerry’s Kids” is certainly laudable, you still might not know what it’s like to live with MD on a day-to-day basis.

For this reason, may I suggest that, before tuning in to this year’s fundraiser, you read *I Hate Muscular Dystrophy: Loving a Child with a Life-Altering Disease*

. Half-hearted memoir/half how-to primer, the book was written by Star Bobatoon whose son, Hurricane, was diagnosed with Duchenne Muscular Dystrophy (DMD) in 2001 at the tender age of 5.

Star was not only pregnant with her second child but employed as an attorney at the time, so the prospect of caring for a kid with a degenerative disease proved daunting, despite the presence of her very doting spouse, Mark. Thus, her initial response of “complete shutdown and denial” was understandable, given the profound effect the condition was about to exact on their lives and relationships with each other.

Eventually, the author came to make peace with the “exasperating characteristic” of DMD, reflecting that, “Just when you think you’ve got it handled, it changes...and “never for the better.” Nevertheless, as Hurricane’s muscles atrophied and he lost the ability to walk, her spirits have remained buoyed by a determination to help him make the most of the time he has left on Earth.

Having learned how to overcome depression in the face of his dire prognosis, Bobatoon lays out a 4-point plan, augmented by exercises and affirmations, for other families struggling to come to grips with MD or any other seemingly all-consuming affliction. Still, it is perhaps fitting to close with the Star’s moving summation that “Living with DMD has made me a stronger, more patient and more passionate person... It has led me to my purpose and for that I am grateful.”

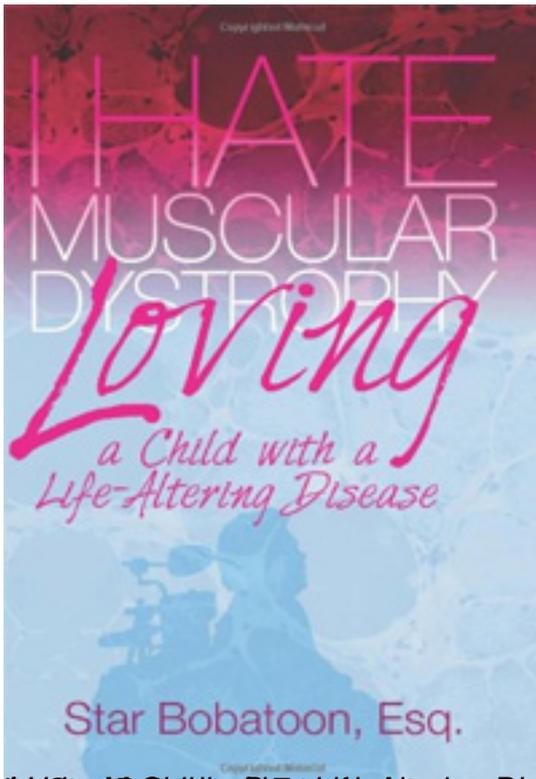
Powerful proof that illness might sometimes serve as a blessing.

To order a copy of *I Hate Muscular Dystrophy*, visit: <http://www.amazon.com/exec/obidos/ASIN/0981711189/ref=nosim/thslfofire-20>

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