

Lessons from Jacob

A Disabled Son Teaches his Mother about Courage

Ellen Schwartz with Edward Trapunski

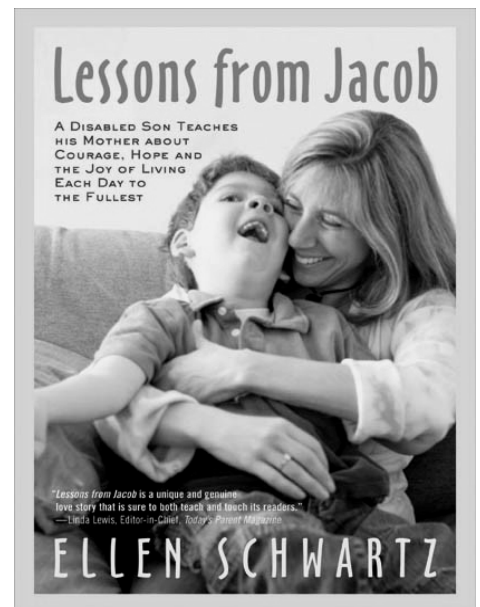
Giving birth to Jacob was supposed to be the happiest moment in Ellen's life. But for Ellen and her husband Jeff, the joyful moment turned into their worst nightmare when after a check-up their doctor at Sick Kids Hospital in Toronto uttered the worst words a parent can hear: There's a problem with Jacob...Canavan Disease. It's a fatal neurodegenerative disease for which there is no treatment. This dreadful disease attacks the central nervous system. There is no cure.

The parents were dumbstruck. Confused. How could this be happening? No, it must be a mistake. And with each symptom it was like another nail in the coffin of her dream of a happy, normal life. Jacob will never see. Jacob will never speak. He will never walk. He will never sit up. He will be as helpless as an infant. There is no treatment or cure. He will die. Maybe in six months. Maybe in two years. No one knew.

In some ways, the worst was yet to come, for not only was Jacob born with a death sentence hanging over his head, but his disease would require as many as eight serious operations within his first year. The unbearable helplessness of a parent forced to endure with impotence the endless agony of a son in constant pain. Pricked so often by painful needles, Jacob instinctively howled with fear when Ellen or Jeff tried to cuddle or comfort him with even the most soothing touch. He required constant, round-the-clock supervision. The strain and stress on the family was unbelievable. And yet, as Ellen painstakingly chronicles in this raw but unforgettable memoir of a mother and her son; "...despite all his disabilities, Jacob loves life more than anyone I have ever met. He shows me how to live each day to the fullest. Jacob is eight years old. He continues, despite the odds, to live each day to the fullest..."

This small hardcover describes seven lessons Ellen has learned from her son to help get her through the bad days, and successfully sail through the good ones.

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Ellen and her family spearheaded **Jacob's Ladder** which has quickly grown into a million dollar foundation that raises awareness, and funds research for other neurodegenerative diseases as well.

For four years, **Jacob's Ladder** has sponsored prizes in genetics to doctors who have made phenomenal strides in their area of study. The prizes have been awarded to international researchers in the areas of Rette's Syndrome, stem cell research, autism, and Gaucher's Disease.