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The Hub for Dying Teenagers: A Call for Change in Organ Donation and Transplantation

Alisha Hiebert

I'm reading a book about sick kids falling in love. It sounds weird, very capitalizing on the "sick lit" trend, but I find these types of novels very comforting.

When I was growing up, I read books about kids with cancer because it made me feel better about my own life. I met my teenage best friend over our mutual love of author John Green and his novel *The Fault in Our Stars*, which was about dying children. John Green was someone who could write about being a dying teenaged girl without actually being a dying teenaged girl, which was true. I was not a teenaged girl dying of cancer, but I was a dying teenaged girl who found solace in reading about teenage girls dying of cancer.

I used to be part of a club started by Steven Spielberg and I promise you I'm not lying when I say that. It sounds insane, the kind of thing people make movies about, but it was true. Cinematic marvel aside, I was part of a group of teenagers brought together by a medical company funded by Steven Spielberg. There was a website with chat rooms and games, and there was one criteria: you had to be chronically ill. We were a hub for dying teenagers.

This stipulation meant I met people from all over the world, who would join this moderated chat room at all hours of the day and talk about medical procedures or how they couldn't sleep because they were in pain. They talked about soccer and movies. They walked me through my first colonoscopy at 15, gave me the best pain relieving tips (ones I still use today), and offered up some of the wisest advice on living I've ever heard. So many things changed in that group from when it started to when it ended, but those golden years were everything.

I met the aforementioned best friend there. I met a number of other people who became my good friends. I understood them in ways not many people did, shared secrets, and song recommendations. I watched them die.

I recently saw through social media that the beloved author of my teenage years, John Green, has written a new book about tuberculosis, and it sent me down memory lane. It prompted me to reach for the "sick lit" on my shelf and scroll through Facebook pages that now say "Remembering" followed by the names of people I used to talk to daily.

One of the things I find compelling now, both as a transplant recipient and also as someone heavily involved in transplant patient support, is how many of the friends I lost were on the transplant waiting list. They spent their days waiting for organs that never came, or they died in surgery. I remember proudly changing my Facebook profile picture to show support for a friend who was receiving new lungs, only to get the news

that he didn't make it. I was still young enough to believe doctors were miracle workers, that transplant cured everything. It was around my fifth memorial attendance when I became disillusioned with the idea of medicine altogether. We were all supposed to have more time, but "more time" just meant more people to remember in their passing.

This was something that never crossed my mind as I was waiting for my own transplant. I know now, and knew then, that statistically organs are not guaranteed, that we have a supply and demand issue. There are more people who need organs than there are organs available, and transplants are not foolproof. People die every single day. I know this, and for the entire time I was waiting, it was as if my brain strategically blocked out the knowing, the awareness that too many friends hadn't made it.

All this remembering made me see how lucky I am. But luck isn't good enough.

Recently, I had the opportunity to attend and speak at a medical conference hosted at NYU Langone, a renowned transplant hospital in New York City. Topics of focus included xenotransplantation, the need for better immunosuppressive regimens, and the supply/demand issue that still exists. Listening to all these discussions, hearing topics spoken about clinically and scientifically, I saw only faces. I saw my friends who passed, long before my involvement in transplant ever began. I saw the faces of everyone who has come to one of my support groups, never to be seen again, and months later I hear from a family member that they have passed. I carry their grief with me, nestled in my chest.

I always thought, when I started this work, that I did it for me. The longer I do this, the more I realize I do it for them.

I think of our little ragtag group of misfits, living our teenage lives within the confines of a hospital, and vying for any sense of normalcy in a way that was both incredibly poetic and incredibly sad. Transplant seemed to be the gold standard then, the beacon of hope. He was supposed to get better after the surgery, she just needed to get the phone call and, like the waving of a magic wand, everything would be okay.

I know now that it isn't true. It isn't that easy. I know I'm one of the lucky ones. It shouldn't have to be that way.

We all deserve better options.

We were only children.

About the Author

Alisha Hiebert is a writer and embodiment coach. She supports patients through her work at Transplantlyfe, facilitating support groups and advocating for patient centered storytelling in transplant care. Email: ahiebert@live.com website: www.alishaemerald.com