

## FOR IMMEDIATE RELEASE

### Rare Disease Community Comes Together to Release Book for Rare Disease Day, February 28

*Sharing Stories from an Underrepresented Rare Disease Community*

**February 23, 2023 — Toronto, Ontario, Canada**

Huntington's disease has been steeped in secrecy and fear for generations, leaving people in the community without a voice. This book changes that. *Huntington's Disease Heroes* features twenty-six people from nine countries who bravely share their personal stories about living in the shadows of this disease. By doing so they are saying: Here I am. I will not be kept silent.

*HD Heroes* is a moving, powerful, and remarkable collection of personal stories from people affected by HD in some way. Their stories must be read by anyone interested in learning more about what makes our HD family community so amazing.

— **Professor Sarah Tabrizi, HD doctor and scientist**

Huntington's disease is a degenerative neurological condition that causes cognitive impairment, uncontrolled movements, and emotional issues. Carriers of the gene will develop the disease—which is said to be a combination of Parkinson's, Alzheimer's, and ALS—but don't know when symptoms will appear.

Canadian author and public speaker Erin Paterson tested gene positive for Huntington's disease (HD). Shortly afterwards she started suffering from depression, then received more crushing news: she was infertile. Despite those diagnoses she was determined to have a family and live a joyful life. She is the author of *All Good Things: A Memoir About Genetic Testing, Infertility, and One Woman's Relentless Search for Happiness*.

Erin is also the founder of Lemonade Press, a publisher that works with underrepresented medical communities to create specialized anthologies about medical conditions and rare diseases. Lemonade Press takes people who are not writers and coaches them through the storytelling and writing process to create captivating personal stories geared towards inspiring their community.

*Huntington's Disease Heroes* includes stories from a scientist who switched from cancer research to studying Huntington's after finding out her mother had tested positive for the disease, a young man whose biggest fear was testing gene negative and not inheriting the disease, and a woman who grew up in survival mode, unable to express her grief.

We learn about the ways their lives are better off because of the hardships they have faced. By sharing these intimate parts of their lives, they are taking away the fear and stigma of living with Huntington's in their families. They are giving a voice to this unheard rare disease community and empowering others to speak up.

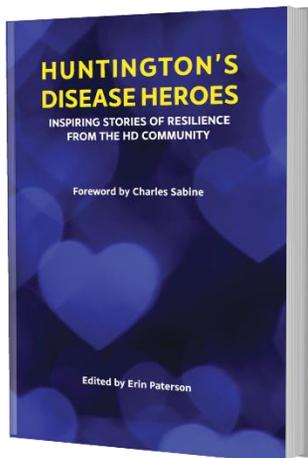
50% of the proceeds from book sales will be donated to the Huntington's Disease Youth Organization (HDYO).

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