

# MIZZOU

The magazine of  
the Mizzou Alumni Association

[Home](#) » [Summer 2009](#) » [Around the Columns](#) » A cause close to home

## Around the Columns

### A cause close to home

Katie Long, 20, a junior in communications at MU, found out two years ago that she carries the gene that causes Huntington's disease, a degenerative brain disorder for which there is no cure.

Huntington's disease is caused when a person inherits a specific mutated gene from a parent, and those who carry the gene usually develop symptoms after the age of 30.

"We didn't even know Huntington's disease was in our family until my oldest uncle died of Huntington's at age 54," says Long of Defiance, Mo. "Then, my mom was diagnosed, and another uncle was diagnosed shortly after.

"Because my mom has Huntington's, I knew there was a chance that I could also have the gene," Long says. "I decided that I wanted to know. In July 2006, I was tested and found out I'm carrying the gene.

"I was really young and went through a



Katie Long, 20, a junior in communications at MU, found out two years ago that she carries the gene

lot afterward, but ultimately it was just the start of a new chapter. Now, I know I can't plan out my life, but I can try to live it to the fullest."

for Huntington's disease. Now, she helps raise public awareness about the disease, which has no cure. Photo by Nicholas Benner

"For Long, that means, among other things, raising awareness about the disease, which affects more than 250,000 individuals in the United States. After learning about her family members' diagnoses, Long established the Hearts for Huntington's fundraising campaign, which has since been adopted as a national campaign by the Huntington's Disease Society of America (HDSA).

"Katie started a fabulous grass roots campaign that could easily be adopted by chapters around the country," says Fred Taubman, director of marketing for HDSA. "The campaign has now raised more than \$100,000 for Huntington's disease programs of research and care." — *Sarah Garber*

### **More Summer 2009 Around the Columns »**



[Follow us on Twitter](#)



[Join us on Facebook](#)



[Subscribe to our feed](#)

---

Published by MIZZOU magazine, 109 Reynolds Alumni Center, Columbia, MO 65211 | Phone: 573-882-5916 |  
E-mail: [Mizzou@missouri.edu](mailto:Mizzou@missouri.edu)

Opinions expressed in this site do not necessarily reflect the official position of MU or the Mizzou Alumni Association.

Copyright © 2021 — Curators of the [University of Missouri](#). All rights reserved. [DMCA](#) and other [copyright information](#).

An [equal opportunity/affirmative action](#) institution.

**Last updated: Feb. 15, 2013**