



Danny



CRAVAT Foundation

Cynthia Pollak



Cynthia

The **C**enter for **R**esearch and **A**nalysis of **V**ascular **T**umors (CRAVAT) is raising awareness of and harnessing research to address one of the rarest forms of cancer, vascular tumors. CRAVAT has its origins in a small but effective support group called HEARD (**H**emangioendothelioma, **E**pithelioid Hemangioendothelioma **A**nd **R**elated **D**isorders),

On September 22, 2008, Cynthia's 29 year old son, Danny, lost his life to hemangioendothelioma. He had tumors in both lungs and scattered throughout his body. When first diagnosed in 1999, he was told his condition was incurable, and there never would be any research, because *'it is so rare, it is not worth the world's health dollar'*. Can you imagine, being told, in this wonderful, affluent 21st century, that your loved one's cancer is not worthy of a cure!

Cynthia established the HEARD website (HEARDsupport.org) including a forum and patient-based registry that stores medical information including diagnosis, treatment, and outcomes. Though supposedly very rare, Cynthia has now collected vital information from more than 300 people - the largest current database of this disease group.

Cynthia's HEARD Registry, (a combination of 200 pages of text), became too hard for her to manage manually, and too hard for members and researchers to read carefully and sort through. So with the help of a team of medical professionals, CRAVAT was created to further the acquisition, validation and distribution of data.

When Cynthia's son passed away, his oncologist stated that the medical profession is still no closer to understanding this disease. How could they be, if there are no major studies into the cause and treatment of vascular cancer? **CRAVAT will change that and the lives of patients with these rare tumors.**

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For questions about the HEARD Registry or to contact Cynthia, please send an e-mail to: info@HEARDsupport.org