Called By Love and Taught By Necessity

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Some people begin an entrepreneurial odyssey pursuing the beacon of a distant aspiration; others begin simply by doing what they have to do.

Two days before Christmas, nearly thirty years ago, Sharon Terry brought her seven-year-old daughter, Elizabeth, to the doctor, to examine a set of persistent bumps on the sides of her neck. Elizabeth and her five-year-old brother, Ian, were diagnosed with PXE, a rare genetic disease that as it advances affects the retina, causing blindness for many patients.

As Sharon and her husband Patrick sought answers, they encountered patients and families facing the disease alone, and a fragmented research landscape that still had not discovered the critical gene. They resolved to break these barriers—by building a community. PXE International took flight. They built a blood and tissue bank, demanding that researchers using this indispensable resource share their findings openly. Patient by patient, researcher by researcher, they built the conditions for discovery.

Elizabeth and Ian grew up, in all the ordinary ways, rising to the challenges of their rare inheritance. The research community and the community of families became more deeply interdependent. In five years, the gene for PXE was identified. Thanks to Sharon's work, the patent belonged to patients and their families, holding the intellectual property as a shared trust.

A cure for PXE remains undiscovered. Understanding the genetic mechanisms of the disease represents the first of many steps. Sharon Terry's work grows outwards, ring on ring, year on year.

Today, she is CEO of the Genetic Alliance, marshaling communities of purpose to uncover the roots of genetic diseases, advance toward cures, and support patients and families as their conditions and their lives unfold.

Is there anything greater to wish for in one's work than, like Sharon Terry, to be called by love and taught by necessity?