

## Two Families Fight Against Rare Diseases

It's everyone's worst nightmare to be diagnosed with a disease. But imagine being diagnosed with a rare disease, one of which there is no proven cure or little medical research about. Imagine the one afflicted with this disease is a child. This is just the situation two families are dealing with, one in New York, the other in Kentucky. The two families' response under such circumstances has been inspiring.

When Caren and Dan Mahar of New York learned their daughter Katie had been afflicted with Xeroderma Pigmentosum (XP), they didn't know where to turn. Individuals with XP must avoid the sun and bright lights because their bodies do not have the ability to repair skin exposed to ultraviolet rays. So what would be a normal exposure of sunlight to anyone else can be catastrophic for a person with XP. The odds of an XP patient getting cancer are great if exposed to ultraviolet light. They must therefore adjust their lifestyle to this condition by staying indoors during the daylight hours. At least 150 people in the United States and 3000 worldwide are afflicted with this disease. There is no known cure.

In 1995 the Mahars founded the XP Society ([www.xps.org](http://www.xps.org)) to help patients and families dealing with the disease. The Society supports medical research for finding a cure as well as providing information to XP patients. The biggest single act of the XP Society is its Camp Sundown where patients and their families gather twice a year. The hours of the camp are structured so all activities are at night when it is safe for XP patients to go outside. This October, Camp Sundown was canceled however, as the XP Society offered its facilities for the potential housing of Hurricane Katrina victims.

Members of the Hollywood community are also active in supporting the XP Society. The actress and director Kimberly Williams produced a short film about the disease, titled Shade. She is currently looking for a film festival in order to debut the film which she hopes will bring more awareness about the disease. Such awareness is crucial to support research into rare conditions such as XP. So little is known about such diseases that attracting the public's attention to raise funds for research is very difficult. It is more likely that an individual will give money to support research into more common illnesses such as heart disease or AIDS. However, the Mahars are quick to point out that "all study on XP will help all people in the epidemic levels of skin cancer worldwide." The Mahars are, of course, not alone in their efforts to raise awareness and funds into a rare disease.

In Kentucky, during 2003 Kara and Dan Heck received the devastating news that their 3-year-old daughter, Malia, had a rare spinal cord tumor. The condition, called intramedullary astrocytoma, was so rare that the Hecks had to go to Baltimore to find a doctor to best treat the condition. A surgery was performed on Malia that removed most of the tumor. Today, Malia is leading a healthy, active life. However, there is the chance the tumor could return as there are small amounts of it remaining in her spinal cord. Unfortunately statistics show that in most cases of this kind the tumor does grow back. The Hecks therefore consider it a race against time to find a cure not just for their daughter but also for the other sufferers of this disease. Last year they founded the Cord Foundation ([www.cordfoundation.org](http://www.cordfoundation.org)) which is hoping to raise awareness of spinal cord

tumors and support medical research for a cure. Currently, the only known research into treating spinal cord tumors is being conducted by Dr. George Jallo at Johns Hopkins Hospital in Baltimore. The Cord Foundation seeks to raise funds to support that research. Thus far nearly 135,000 dollars has been raised but more is needed. The Heck family believes research into spinal cord tumors will also benefit the treatment of other types of tumors.

Two families that are nearly 800 miles apart, but with similar missions: To raise public awareness and support research into two rare medical conditions. It's a tough chore for both the Mahars and the Hecks. Any support for their two organizations, no matter how small, will help those afflicted with these two diseases and encourage groundbreaking research into discovery of a cure.

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