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June 4, 2007

MY VIEW: MARY CATHERINE COLLET

Help us connect dots by collecting the dots

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Sometimes it's hard to know the difference between the normal aches of getting older and those things that should really cause worry. While enduring a long wait to get on a physician's calendar or to receive some test results, who hasn't thought, "If it's really bad, here's what I'll do?"



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Typically, we all aspire to be Lance Armstrong in the face of a catastrophic diagnosis. We Americans have been taught to gather all the information we can seek the best medical help available, and fight diseases with all our strength. For millions, courage and science have overcome what would have been certain death 50 years ago.

Every 90 minutes, someone in this country goes to the doctor and is told that slurred speech or loss of dexterity is caused by ALS (amyotrophic lateral sclerosis), better known as Lou Gehrig's disease. When you get that diagnosis certainly you want to do what Lance Armstrong would do. Within a few days of seeking information and the best medical care in the field, newly diagnosed PALS (people with ALS) learn something that is outrageous. Unlike that of cancer patients, their outlook is the same that the New York Yankee great face 68 years ago. It's a death sentence, still. There is no known cause. There is no cure. There are promising experimental treatments, but "promising" doesn't cut the mustard when you've been given an outlook that involves a steady decline death within several years.

ALS gets little attention from medical researchers. The patients die so quickly that there aren't enough living at any one moment to get the attention of pharmaceutical companies and major research funding.

Since Lou Gehrig gave his farewell speech in 1939, more than 350,000 people have been lost to ALS in the United States. Every day an estimated 15 Americans die from ALS and 15 get the diagnosis.

Those estimates are particularly frustrating. There is no census of PALS. We lose valuable clues every time someone dies from ALS. That is why seven Hoosiers met with 10 Indiana legislators on Capitol Hill in May to ask them to support national ALS registry. We can't connect the dots if we're not even collecting the dots.

Adding to the outrageousness of this disease is the fact that veterans of military service are twice as likely to be diagnosed with ALS as those who have not served. In light of this fact, Indiana voters also wrote hundreds of letters encouraging support for increased research funding from the Department of Defense.

Most of us have known someone who has died from ALS. It is up to those of us left behind to increase the noise level about this terrible disease so that the time and money are allocated to find a cure. Please consider representing your teacher or minister or loved one or co-worker or neighbor who died from ALS by participating in local events that give visibility to the cause and that add valuable support services to PALS who are dealing with the disease today. The ALS Association of Indiana (www.alsaindiana.org) provides such events and services throughout the state.

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