LETTER FROM THE EDITOR

atients often bring me articles or clippings to read, and occasionally a book they think I would enjoy. Generally, the books end up on my ever-growing pile of unread pages. The articles about herbal or other Merlinian therapies are summarily discarded. However, I try to at least scan the reasonable articles they are thoughtful, or curious, enough to provide. The other day, one patient who has become a close friend, and has been on our Lymphoma Research Ride Committee from its inception, e-mailed me a New England Journal article from 1981. She had initially been treated on a phase III lymphoma vaccine trial for her follicular lymphoma and had a modest response to the rituximab induction therapy. When she recurred, she still wanted to avoid chemotherapy and was, therefore, treated with Y90 ibritumomab tiuxetan. She remained in a complete remission for almost 5 years, when new nodes were identified which were of a sufficient size to warrant therapy. Although always cheerful and apparently strong, the reality of her mortality when she had relapsed threw her into a tailspin. A long-time supporter of what I do, she nonetheless refused another clinical trial, and is now finishing her 6 cycles of bendamustine-rituximab. The article she sent was by Alice Stewart Trillin, late wife of the famous humorist Calvin Trillin (who once said "Health food makes me sick!"). She died in 2001 from lung cancer attributed to secondhand smoke. Anyway, her article was entitled "Of Dragons and Garden Peas: A Cancer Patient Talks to Doctors (New Engl J Med. 304:699, 1981). My friend began to be troubled by anxiety when she recurred, and she started to see a counselor who suggested she might enjoy reading the "Special Article." Rather than my summarizing what I thought was a particularly interesting reflection, I asked my patient/friend why it impressed her so much. After a day in the chemotherapy chair, this was her response:

"The reason I liked the article is that I identified closely with many of the things she experienced. She starts with what changes both with the patient and with others when a person is labeled as having cancer. Her experience was that people perceive cancer patients as people who are altered forever. My experience is that friends and family have been very concerned and supportive, but at the same time (with the exception of [my husband]) completely separate from my experience. She calls it 'The Land of the Well People.' I love that description! The well people can't know what the patient is going through, but they know the patient is no longer in the

group. She then goes on to talk about defense mechanisms or talismans that are essential to keep one's sanity and not live in a constant state of anxiety and fear of dying. Similarly, I have adopted a series of defense mechanisms that work well for me to be happy even while coping with the knowledge that my disease will not go away. I did not relate to many of her points about doctors and especially do not relate them to our relationship. For example, the notion of losing faith in doctors because treatments fail did not resonate with me. Nor did I agree with her that the best way to please a doctor is to get well or that docs get angry if patients do not respond to treatment. I do think docs get frustrated and disappointed when treatments fail, but this is aimed at the disease and not at the patient. I have done research, spent time understanding the disease, and know that the bottom line is there are no guarantees. With all that said, I do think that I am a very well-behaved patient, wanting to be positive and upbeat, so that people like and respond well to me. That is definitely part of my personality in most things, and not isolated to Georgetown and Lombardi. The part about the 'brave act' to exert some kind of control of the irrational forces that are loose in the body is something for me that is important. It keeps me happy and positive and as Trillin says-it is the way to convince those who live in The Land of the Well People that we aren't all that different from them. Finally, she talks about the way to avoid fixating on death is to concentrate on the details of everyday life. It doesn't mean that you don't ever confront the fear; it just means you don't dwell on it. I feel that I have achieved that balance and live with a great deal of joy. She says and I agree, that the reason that people with cancer often say that their life is so much richer, is because they have confronted death, then moved on to try to get as much out of their life as possible."

Don't expect me to top that one.

Until next month . . .

Ince D Cheson

Bruce D. Cheson, MD