



# IN MY VIEW

## SOCIETY HAS A RESPONSIBILITY TO TREAT PATIENTS WITH GENETIC DISORDERS

**I WANT TO TALK ABOUT AN INJUSTICE.** I believe there is something fundamentally wrong in our society when outrageous sums of money are spent dealing with the negative effects of tobacco use in the United States when at the same time patients with life threatening diseases must routinely face gigantic hurdles to access healthcare. I recently read an article that made me think about the issues that we are dealing with on a daily basis. This is what I read:

*Excerpt from:*

### **FDA Regulation of Tobacco Products**

By Lawrence R. Deyton

Source: "Food and Drug Law, Regulation and Education," May/June 2011 Edition

"It is difficult to overstate the toll tobacco use has taken on the United States. Each year smoking kills approximately 443,000 Americans; more deaths than from HIV/AIDS, alcohol use, cocaine use, heroin use, homicides, suicides, motor vehicle crashes and fires combined. No fewer than 8.6 million smokers suffer from at least one serious illness. In addition to its incontrovertible impact on public health, cigarette smoking also has a corrosive impact on our economy. We now know that smoking generates \$96 billion in medical costs and robs our economy of \$97 billion in productivity annually just from those who die prematurely. Yet, today, 26 percent of U.S. high school students currently use tobacco products. In addition, an estimated 4,000 young people start smoking each day and 1,000 kids become regular smokers."

The costs for self-induced illness are exorbitant—the article quoted above provides the numbers to flesh out the extent of the problem. Even with today's understanding of nicotine's deadly attraction, cigarette

smoking, pipe smoking, etc., seem to be accepted by our society. I will not deny individuals the right to smoke in such a way that their smoking does not endanger others around them. That is a personal decision that everyone has the freedom to make. Every person who uses tobacco products is informed about the risks and understands the consequences. I must accept that these people not only choose to pay large sums of money for their addiction, but expect the U.S. healthcare system to help treat the common illnesses that result. I find it more difficult to accept that society has to pay for the costs associated with that personal decision.

What about the many patients that we serve? Whether this is hemophilia, immune deficiency, alpha-1 antitrypsin deficiency, hereditary angioedema, chronic inflammatory demyelinating polyneuropathy, none of these patients made a voluntary choice to have this condition, most are genetic disorders that they were born with. The struggles to get the right diagnosis, treatment and payment are enormous. Every month I hear new stories that confirm that.

The patients we are dealing with are small in numbers. The number of patients that our entire industry is serving does not even meet the criteria for an orphan drug in the

United States (patient population less than 200,000). Yet, the costs of these therapies must be shared by this relatively small population and are higher compared to small molecule drugs that are used by millions of people. We have a societal responsibility to treat people with genetic disorders. They did not choose a lifestyle that induced their illnesses and they deserve an improved quality of life. We also have a societal responsibility to correct what seems to be wrong. If we can afford almost \$100 billion per year for self-inflicted diseases we have to ask the question: "Is this what we really want to do?"

