3-26-2010

Good-bye, pre-existing conditions!

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Digital USD Citation
Serbin, Kenneth P., "Good-bye, pre-existing conditions!" (2010). *At Risk for Huntington's Disease*. 63.
https://digital.sandiego.edu/huntingtons/63

At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

FRIDAY, MARCH 26, 2010

Good-bye, pre-existing conditions!

No matter what you might think about the new health care reform law, it's hard to disagree with one of its key provisions: a guarantee of coverage for people with pre-existing conditions.

The law signed by President Barack Obama on March 23 immediately prohibits insurance companies from denying coverage to children with pre-existing conditions. In 2014 the law will extend that protection to adults.

The law especially gives people in the Huntington's disease community a big reason to celebrate. I felt especially moved, because I am gene-positive for HD.

HD is a genetic disease, and children of affected parents have a 50-50 chance of inheriting it. Even before testing, those offspring are already considered "at risk." This situation caused many HD families to go underground regarding their status to avoid loss of health coverage or denial of a new application.

These people also had little incentive to get tested. If they did test and the results were positive for HD, their medical records would already indicate to health plans and insurance companies that they would develop a deadly brain disease requiring long-term medical attention and expensive medications such as tetrabenazine. Death occurs as long as 20 years after the onset of clinical symptoms. And, depending on how early in life they tested and how severe the genetic defect, the onset of symptoms might not occur for many years or even decades – or it could be imminent.

Insurance companies had little incentive to take on such individuals. HD is the quintessential pre-existing condition. *Everybody* with genetic defect eventually becomes ill.

The new health care law prevents this discrimination, and one of its provisions will reduce the cost of policies for people with pre-existing conditions. Another important part of the law ends the cap on lifetime benefits. Insurance plans can no longer drop people who get seriously ill.

Liberating legislation

Rep. Nancy Pelosi (D-CA), the Speaker of the U.S. House of Representatives, summed up the potential impact of the new law. "It's liberating legislation," Pelosi was quoted as saying in *The New York Times* on March 21. "It's to free Americans to live their passion, reach their aspirations without being job-locked because they have to have health care, especially if they have someone in their family with a pre-existing condition."

As we all know from the heated debate over health care reform the past year, many people opposed changing the system. Indeed, as President

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GENE VERITAS

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Obama had barely signed the bill, various elected officials and state attorneys general said they'd seek to repeal or block implementation of the legislation.

I've heard no complaints about the provisions regarding pre-existing conditions. No matter what people's position with respect to the overall legislation, I hope that any attempt to change it will not result in excluding this historic protection. A lot could happen between now and 2014, when the legislation takes full effect.

The issue of pre-existing conditions transcends politics, and I hope leaders of all political persuasions see it this way.

As scientists develop genetic tests for more diseases, more and more people will have "pre-existing conditions." The genetic basis of disease is becoming ever more apparent, and personalized medicine – where each individual gets specifically designed medications based on his or her genetic makeup – could become a reality in the coming decades. Someday we may all have at least one, if not several, pre-existing conditions.

Furious about insurance

As with the stories of many other Americans, my own history with the health care system demonstrates the necessity of the reform.

Like so many of us, I learned the dreaded term "pre-existing condition" as I came of age in the 1970s. I remember filling out insurance forms that asked questions about all kinds of conditions. I developed a profound dislike for the health insurance industry and also the way our health care system in general worked.

What good was insurance if you could be rejected for so many reasons?

One day in 1992, the inhumane and illogical nature of the system became crystal-clear. I had recently been diagnosed with asthma by a doctor in Indiana. Now, on my first consultation about my condition after getting a new job in Florida, I couldn't believe what was happening.

The physician basically grazed her stethoscope across my chest, made a couple of comments, and left the consultation room. The entire appointment took no more than a few minutes.

In the waiting room prior to my appointment, I had heard the doctor ordering a secretary to call home and have someone take care of her Mercedes.

I was furious after I left the doctor's office. Later I made a formal complaint. And I then I went back for a follow-up appointment.

A backwards system

This time the doctor looked rather guilty. She actually took a few minutes to listen to my breathing.

Then, at the end of the consultation, she told me, "If I were you, I wouldn't tell anybody that you have asthma."

She said this as if she were doing me a special favor to make up for the lack of attention during our first meeting.

I felt in my gut how our health system was based on backwards criteria. The patient was at the complete mercy of this system. In fact, the patient had *no place* in the system if he or she actually had any kind of serious condition.

A long, frustrating experience

When I learned in late 1995 that my mother had Huntington's disease, I wanted to get tested immediately. But my mother's neurologist warned me to be extremely careful and to take my time to decide about testing. People could be denied health coverage if they tested positive for HD and revealed this information, he explained.

Thus began a long, frustrating, and painful experience of keeping quiet information about my mother's illness and my at-risk status.

This experience intensified after I tested positive for HD in 1999. I kept my HD status from virtually everybody – employer, professional colleagues, health plan, financial advisor – to assure that it did not enter my medical or other records.

Although I have reached the height of my career potential, I have been afraid to look at new job opportunities. I have group health coverage, but what if a potential new employer does not offer such coverage? I would have to lie about my HD status.

Going outside the plan

Worst of all, I have never used my health coverage to help me deal with the central fact of my health: my gene-positive test for this horrible brain disease.

I got tested for HD outside the plan, pay out of pocket for check-ups at the local HD clinic, and have paid tens of thousands of dollars in fees to a private psychotherapist, who has helped me cope with living at risk.

The need to hide my HD status is one of the main reasons I use the pseudonym "Gene Veritas" in this blog.

I wish that protections for those with pre-existing conditions had come about long ago. I could have lived without fear of losing coverage. I could have received all of my medical care within a single plan and thus strategized more confidently about avoiding symptoms. I would have felt much freer to pursue better job opportunities.

And I would have lived with far less stress.

Safe at last

Several times this past week I've breathed a sigh of relief about these forthcoming new legal protections for people in my situation. I'm edging ever closer to coming out of the HD closet and becoming more public in my activism for the San Diego chapter of the Huntington's Disease Society of America. I will feel a lot safer knowing that I'm covered no matter what.

It's also a great psychological boost, key to maintaining basic health in order to stave off the inevitable symptoms as long as possible.

But the new law won't so much as help me as it will the younger people from Huntington's families who are just beginning their lives and the difficult process of deciding whether to get tested, change a job, or start a family.

I'm also hoping that the new law will give untested at-risk people the incentive to discover their status so that they can assist with HD research and clinical trials. An increasing number of potential drug targets are entering the pipeline, and labs need subjects to test them.

We can now happily begin to say good-bye to "pre-existing conditions" in our health care system. This week brought a new beginning for the Huntington’s disease community – and for everybody in America.

Posted by Gene Veritas at 9:23 PM

1 comment:

becky said...

hd runs in my family,call i dony know what to do,502 538 7109.i have no insurance.I cant get help im a college student too.very nice article

7:42 AM, February 19, 2011

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