



In My View

BY JAN M. BULT, PPTA PRESIDENT & CEO

The challenges in the newly begun 2017 are no different than they were in 2016, but there is uncertainty about what will happen this year. Patient access to care remains the single most important issue. A lot of work needs to be done by all involved parties to ensure that patients have access to their (many times life-saving) therapies in all sites of service. There should be no exception. This should apply to all countries in the world.

Am I dreaming or living in Wonderland? Sometimes I cannot believe all the terrible things that are happening in the world that affect so many innocent people. I remember the concerns of our Brussels staff (while at the International Plasma Protein Congress in Barcelona) about their families after the airport and subway attacks.

The patients we care about are innocent because none of them asked to be affected with a genetic disorder and always have to “fight” for their legitimate treatment. When I mean fight I am talking about problems with reimbursement, coverage, availability and so on.

As I am writing this, there are many questions about what will happen in the United States with the Affordable Care Act (ACA) also known as “Obamacare.” The Republican Party has said many times that they want to repeal the ACA as rapidly as possible. Then the President states that he wants to keep certain parts—like the provisions that allow children 26 years old and younger to be included on their parent’s policy—and not exclude pre-existing criteria for newly insured persons. What about the elimination of the lifetime caps that patients fought so hard for? Is this going to stay or not? It may well be that when this column is published, we will know more, but today there is uncertainty. And that is unfair.

Persons with genetic disorders who rely on life-saving plasma protein therapies already have enough on their mind. They do not need additional worries.

We are going to have many elections in various countries such as France, Germany, The Netherlands, and more. Every time when an election is near, issues come up about health care and price of medicines. And every time we have to explain why our therapies are so different:

- Small patient populations
- Rare diseases
- Different starting material with additional regulations
- Complex, lengthy, and expensive manufacturing processes

The good thing is that we have done it so many times that the arguments are in our veins. The arguments have to be conveyed to the various policymakers and payers in the many countries where these debates are held. Nowadays it seems that it is everywhere.

The good thing is that many times we are successful. Be assured that we will continue to help. You can count on us! ●

Jan M. Bult, PPTA President & CEO