

August 24,2011

To: The Honorable Members of the Senate Banking and Insurance Committee and Interested Senate Members

Re: The UPMC/Highmark Provider Contract

Thank you for the opportunity to submit written testimony in support of a resolution to the ongoing matters with respect to UPMC and Highmark in Western Pennsylvania.

I am 37 years old and have been living with Multiple Sclerosis since 2003. I actively serve on the National MS Society's Program Committee, PA Collaborative Action Network, Western Pennsylvania Government Relations Committee, and have participated for 4 years in the Annual National MS Society's Public Policy Conference in Washington D.C., while being a guest speaker at the 2010 Conference.

Myself, along with the support of the National MS Society are aware of the major changes taking place in the health care and insurance market place in Western Pennsylvania. These include negotiations involving contractual arrangements between certain stakeholders in the provision of care to people with MS that remain un-resolved at this time. The fact that these negotiations remain unresolved is creating a growing sense of alarm among people with MS, their families, and caregivers.

The National MS Society's primary concern is for the welfare of individuals afflicted with MS. If negotiations between affected providers and payers of MS care are not successfully resolved by June 30th 2012 , people with MS may no longer have access to in-network healthcare providers and services offered through the University of Pittsburgh Medical Center, its affiliates, and/or the West Penn Allegheny MS Treatment Center.

It is vital that patient concerns, care, and rights are discussed, addressed, and considered carefully as our State reviews the impact of the UPMC/Highmark negotiations. The National MS Society and its partners want to be assured that the 'voice' of patients is heard during this process.

One concern between the two MS Treatment Centers here in Pittsburgh, is over the monthly infusion therapy Tysabri. Tysabri is a drug that is administered intravenously every 28 to 35 days and has strict guidelines associated with it because Tysabri increases your chance of getting a rare brain infection that usually causes death or severe disability. This infection is called progressive multifocal leukoencephalopathy (PML). PML usually happens in people with weakened immune systems. Because of this fact, Tysabri carries a Boxed Warning from the FDA. *(According to the FDA, a Boxed Warning is the most serious warning for a prescription medication. Boxed Warnings are designed to highlight important safety information and to help doctors and nurses understand what they are and how to deal with them.)* The Boxed Warning for Tysabri warns of the increased risk of PML and the importance of monitoring patients using the drug for any new sign or symptoms that may be suggestive of PML.

Given the above stated, one can see the importance in continual care, monitoring patients, and the delicate nature of the doctor/patient relationship. As an individual battling the progressively debilitating, chronic disease with no cure that is Multiple Sclerosis, it is vital my disease progression is managed in a continual, seamless fashion. With the proper care, it is proven that some of the cost burden on my health care provider can be reduced through preventative medicine. Left to deal with this disease for the balance of my life, one can not underestimate the importance of the doctor/patient relationship. These relationships have been built over time and are in jeopardy of being negated by cost barriers such as out of network costs.

Another concern in the MS Community is the lack of MS Neurologists in the lesser populated areas of Western Pennsylvania. In Erie for example, there is one MS Clinic and it is associated with UPMC. What will happen to a Highmark insured MS patient? A neurologist who once was 'in network' is now 'out of network' creating an entire host of obstacles for the MS patient. Where would a Highmark insured patient with MS go to get his/her Tysabri infusion? And at what cost? The Tysabri drug and infusion run approximately \$48,000 per year. This individual would be faced with an out of network payment on \$48,000 or find another in network qualified MS Neurologist that could be hours away.

These unresolved issues between UPMC and Highmark may also result in, but not limited to:

- ◆increased claim and administrative burdens for patients, caregivers and providers;
- ◆longer waiting times for appointments and shorter encounter time (appointments) between patients and their health care team;
- ◆increased confusion about coverage and payment issues straining systems and resources of payers and providers alike; and
- ◆threats to the quality and outcomes of care overall.

As a result, we believe, that as a State, it is also important we review the Pennsylvania Patient Bill of Rights and consider any change that may better reflect the health care environment as it is today.

Again, myself, the Society and its partner organizations, the Consumer Health Care Coalition and the Greater Pittsburgh NonProfit Partnership urge our state officials to help resolve the disputes between stakeholders as quickly and reasonably as possible.

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