



January 21, 2015

Illinois Hepatitis C Task Force

Re: Public Testimony from Caring Ambassadors Program on 1/21/2015 Task Force Meeting

Dear Chairman McAuliffe, Co-Chair Munoz, and Committee Members:

My name is Dr. Navin Vij and I come to you today as a physician, an advocate and a patient. I testify on behalf of the Caring Ambassadors Program, a nonprofit organization dedicated to empowering people to be ambassadors to their own health. We strongly urge the Task Force to be a BOLD vehicle for statewide, system change.

As a hospitalist at Case Western Reserve University in Columbus, Ohio, I have firsthand experience with the growing burden Hepatitis C has had on the medical system. Despite being the leading cause of liver transplants and now the fastest growing cause of cancer deaths in the US today, Hepatitis C has been a silent killer. Most patients living with the disease don't know they're infected and beyond that, many who do know their diagnosis have failed to pursue treatment for fear of the side effects – a fear that no longer needs to exist.

My story as a patient goes back...to the last week in June, 1983 in Minneapolis, Minnesota. I had just hit 29 weeks of development in my mom's belly and I had had it – I was done...I wanted freedom and I wanted out. So with my own efforts to drive up my mom's blood pressure, that is what happened and with it, I spent the next several months in the Neonatal ICU while my mom spent them by my side. Breathing tubes, chest x-rays, blood draws, and blood transfusions all ensued. When many asked my mom – "how could this happen," and "what will you do," my mom used to shrug with a smile and say "everything happens for a reason – the challenge in good and bad is to find out why."

27 years later, I found myself in Employee Health Services, post-call from a 30 hour shift and reluctantly waiting to get my blood drawn after an accidental needle-stick during a procedure. I was tired and really just wanted to go home...plus minus a stop for an Egg McMuffin. A few days later, I received a phone call that forever changed my life. "You have Hepatitis C."

The questions abounded. "Excuse me – you must be wrong. How could this be?" "Do I have cirrhosis?" "Am I going to need a liver transplant?" "Can I still work in the hospital?" "How do I tell my family...my friends...my girlfriend?" What kept coming back to me were my mom's words: "everything happens for a reason – the challenge in good and bad is to find out why."

A few days after my birthday in 2010, I gave myself my first injection of interferon and took my first ribavirin pills. Over the next 6 months, I would become well versed in what many of my own patients had experienced – the flu-like feelings for days on-end, changes in mood with occasional delirium, and of course – the infamous ribavirin rash, which left me red, itching, and awkwardly scratching myself in front of patients. Then there were the multiple days of neutropenia – days where the total number of neutrophils in my body (white blood cells responsible for helping one's immune system fight infections) was severely low. Despite some setbacks and the myriad of lab draws, I got through it and one year later, in July 2011, I was declared cured from my Hepatitis C.

As a physician, I have often found myself struggling over why things happen to some people and not to

others. I often used to think that much of what happens to “patients,” particularly adults – is something of their own doing. “They ate bad for years...or they smoked and drank for 50 plus years.” And yes, it is true that as providers we can logically ascribe certain disease states and their consequences to decision-making on the part of individuals. However, this approach prevents us from fully understanding the magnitude and meaning that a diagnosis of a disease like hepatitis C has on a patient’s life- specifically, it fails to acknowledge the intimate emotional, spiritual and physical challenges they will endure throughout their treatment and the terrifying uncertainty of what their future holds.

I look back on the last several years, and despite their challenges, I know I was lucky. I was fortunate to get needle stuck and learn of my diagnosis. I was fortunate to be young and have more reserve to tolerate the treatment. And I was fortunate to live in a time that had great drugs that have changed the game of treating Hep C.

An estimated 3 million people living in the US are infected with Hep C but nearly 75% of them don’t know. We need to do a better job and the State of Illinois needs your help. With new drugs emerging on the market that have dramatically increased cure rates and virtually eliminated the nasty side effects mentioned earlier, it is imperative that we help as many family members and friends know, through increased screening efforts, so that they too can learn that being diagnosed is not bad news, but can actually be something good that happens for a reason. We need to talk about hepatitis C with our patients, our colleagues, our friends and family- to remove the blame that is so often assigned to patients who carry the diagnosis, so that they are not afraid to seek help and ask for support from those around them- which they will undoubtedly need throughout their treatment journey.

So, as a governor appointed task force, what can you do? Currently, Illinois has the most restrictive prior authorization for Medicaid approval of HCV treatment of any state in the country. Eliminate these harsh restrictions. The United Network for Organ Sharing estimated that the average cost of one liver transplant is well over \$500,000. Ask yourself what makes more sense – spending taxpayer money on such costly and irreversible options – or investing in the future of Illinois by preventing – preventing the complications of Hepatitis C and with doing so, preserving the life of many in Illinois so that they too can positively contribute to society. Gather data and understanding about how many in Illinois are living with HCV and how the state is impacted. Educate – the public, each other, and the medical community about the new reality that Hep C is curable and that new treatments do not carry with the scary side effects that previously have deterred so many from seeking help. Finally, support funding and legislation for integrated screening efforts and testing – so that thousands can simply know of their diagnosis.

These are areas the Task Force can take on. Such small steps can expose the workforce, legislators, patients, and communities to life-changing information. There is no one group that lives with or without the impact of hepatitis C – it affects every one of us. I look forward to seeing the positive changes that your state has the opportunity to make through your Task Force, creating access to much-needed healthcare for thousands of Illinoisans, and eliminating the unnecessary stigma to those living with hepatitis C so that they too can say, “I’m cured.”

Thank you,



Navin Vij, MD
Hospitalist
Seidman Cancer Center, Cleveland, OH