

Dear Chairwoman McIntosh,

I am Anupam Sidhu and I ask you to support this bill favorably.

In the United States, per cdc.gov, more than 40% of school-aged children and adolescents have at least one chronic health condition,¹ such as asthma, obesity, other physical conditions, and behavior/learning problems. Meanwhile, 60% of adults are said to have at least 1 chronic illness.

A chronic condition “is a physical or mental health condition that lasts more than one year and causes functional restrictions or requires ongoing monitoring or treatment” [1,2]. Chronic diseases are among t

A recent Milken Institute analysis determined that treatment of the seven most common chronic diseases coupled with productivity losses will cost the U.S. economy more than \$1 trillion dollars annually.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5876976/>

I have the unique position of being Physician and an adult with multiple chronic conditions that began in childhood.

As a child, I was considered ‘lazy’ as I had little energy to run, jump or play. I rarely played sports, by 4th grade could not run a mile, climbing stairs was often exhausting and I would have days where I felt competently exhausted upon waking up. Somehow, I managed to keep up with school. I would intentionally work harder on my ‘good days’ so I could coast on my ‘bad days’.

Things became harder when I was in Medical School, where every day and every class is crucial. Still, I managed to keep up, graduated, finished a competitive Family Medicine Residency and have now been practicing for nearly 13 years.

I wasn’t given my first diagnosis until I was 23, when I was already halfway through medical school. Then in Residency, I was diagnosed with Idiopathic Chronic Angioedema. 6 years later I was diagnosed with a food sensitivity that, in hindsight combined with my Angioedema had likely caused many of my symptoms since childhood.

During school, because I was undiagnosed, I coped by telling myself I was lazy, and I need to work harder. I didn’t know there were actual medical reasons for why I couldn’t function like my peers. Yet, I managed to keep up and felt I did well, considering. I feel my success is directly linked to my significant support system in my friends and family. Financially, my parents were able to support me through school, so I didn’t have to juggle work and school.

Sometimes, I think, if I could have done this with undiagnosed, untreated chronic conditions with no assistance or accommodations from my school, imagine what else I could have done with a little extra help during my flares. My test scores were always lower during flares. Fortunately, I would do well enough to average well when I was feeling well.

However, I understand many of my Chronic Illness Warrior friends have chronic illnesses that often render them unable to perform in school at times. Meeting deadlines when you've just recovered from an unexpected seizure or Multiple Sclerosis flare may be physically impossible.

Having a Case Manager to help navigate these unique challenges could be incredibly impactful.

As a physician, I see many of my intelligent, determined and ambitious patients crave purposeful education and careers. Many of these young patients end up leaving school due to not being able to juggle work and school while also managing their chronic condition. Often, after missing too many classes or assignments, they must drop classes or quit school completely. They don't choose to stay home; they are forced to stay home because the society we live in has not made space for their unique set of needs. I see the light and excitement in their eyes slowly fade as their ambition turns into practicality and defeat. It's heartbreaking.

Pediatric patients have access to assistance from parents, school counselors and care coordinators.

In the hospital, case managers effectively improve care coordination, therefore reducing hospital length and preventing readmissions.

Medicare patients often have access to Case Managers who help coordinate social services, home health, physical therapy, medication refills and follow up appointments.

There is a clear void of assistance for young adults who are leaving pediatric services but not yet qualifying for Medicare Services.

Areas I see Case Managers assisting College age Chronic Illness students would be:

Assisting with determining an appropriate education plan based on abilities, appropriate housing based on physical functions, navigating financial aid and communication with educators for necessary accommodations. With these additional tools, in the long term, I believe society would benefit from the investment in these young adults.

I deeply appreciate you taking the time to listen to my story.

Before I met Invisible Wave Movement, I had never even considered that I deserved additional support based on the obstacles brought on by my chronic illnesses. I believed it was solely my problem to figure out and handle on my own. It was lonely and difficult. With this new bill, I less lonely and hopefully easier for these ambitious young adults.

I sincerely hope you will consider passing this legislation to help support Chronic Illness young. I want them to know they deserve support and that we support their efforts in achieving meaningful contributions to our society.

Thank you,

Anupam Sidhu M.D.