



Comments PDAB -PDAB- <comments.pdab@maryland.gov>

Victoria Sampson

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To: Comments.pdab@maryland.gov

Mon, Nov 27, 2023 at 11:58 AM

Board,

I am writing because I am deeply concerned about your upcoming ruling. I was a caregiver for my uncle who suffered from progressive multiple sclerosis. For twenty years, we watched his health slowly decline. He went from being a fiercely independent man—we nicknamed Superman—to a man who was dependent on us for all of his tasks for daily living.

When he was diagnosed in 2000, there were few treatments available. Over the years, he slowly lost his ability to walk and even stand. He then lost his ability to use his left arm. While we all watched, helpless, he was only offered interferon beta as treatment. Today, thanks to research and innovation, people living with multiple sclerosis now have numerous options available and more on the horizon.

I fear that the imposition of upper payment limits will not only hamper access to these innovative treatments but also impact research. When I see the progress made in multiple sclerosis, it is bitter sweet. I wish my uncle and family could have benefited from this progress. His suffering was our suffering. I am still haunted by the fact that he was essentially a prisoner...not only of his body but also the house. Over the years he suffered from this disease we lost him multiple times. In the end, he feared the hold his disease had over his body. To know that others have access to treatment that could halt the progression of this devastating disease gives me peace.

Please do not make any ruling that will restrict access to innovative treatments for people who have no hope. Please do not impose upper payment limits for rare disease drugs.

Thank you,
Victoria Sampson

Sent from my iPhone