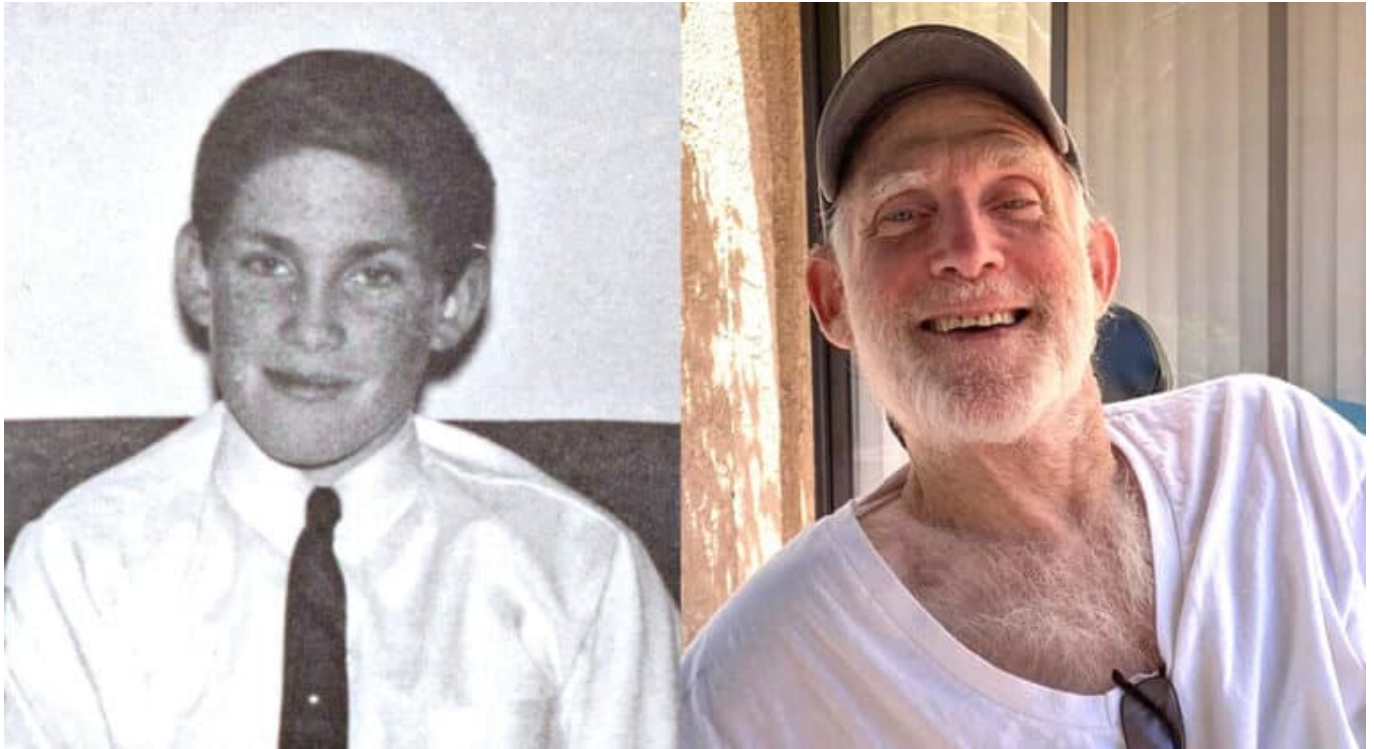


Donating My Brother's Organs to MS Research



Editor's Note: Everyone has their own unique journey with MS, and The National MS Society blog strives to amplify the diverse perspectives of people in the MS movement. While the content of this blog may be sensitive to some, the author is sharing her family's personal, authentic journey with MS.

My brother Steven was diagnosed when he was 33 years old. When his disease progressed and became growingly more difficult for him, I noticed a decline in his executive functioning. As his sister, I picked up the ball and helped him in any way I could — from securing MediCal to making doctor's appointments for him. He leaned on me, and I was so happy to consistently be there for him. I watched over him and protected him. Our relationship deepened, we grew even closer through this and became a team.

One day, I was creating a trust for myself and my daughter for the day — that is as uncomfortable to talk about as it is inevitable for all of us — the day we die. I was telling Steven about it. He didn't have a lot of assets, so he didn't really need a will or trust, but we talked about funeral arrangements for when that day would come for him.

He had two wishes: to be cremated and to have his body donated to MS research.

Now, there's something about Steven you have to know — he was rare and unique in the way

his gentle manner put others at ease. I never quite understood how he could be so consistently positive about his situation. Inside of him was gentleness and goodness that lit up his bright blue eyes even in his darkest moments. His request to donate his body fit with his incredible attitude and the way he thought about his life; the way he wouldn't give in to MS. He was a deep thinker and thought beyond himself, always. He wanted to help somebody else in the future that had MS.



I put that conversation away in my mind until late 2022, when he suddenly and unexpectedly passed away at the age of 67.

My family wanted to honor his wishes. As hard as it can be to “give away” a part of your loved one to even what is a noble cause, I personally thought it was such a gift Steven was giving to mankind — a beautiful offer he wanted to do. So, I just followed through with it after he passed.

I didn't know where to start, so I searched on Google, and it all came together. I got in touch with a team from the National Institutes of Health who are conducting a study for people living with MS who wish to donate their brain/spinal cord upon death. They put me in contact with a research team at Columbia University that is carrying out the study, and they handled everything.

The idea of [**donating the body of a loved one to research**](#) is hard to think about, but the research team at Columbia University took his body from the mortuary and removed the

brain and spinal cord and brought him back to the mortuary. We saw his body again afterwards and couldn't even tell.

As hard as this process was, it was what Steven wanted. It may not be something that everyone wants to do, but I think it's beautiful.



His donation was a gift to all the other current and future people living with MS. It will give researchers the ability to do important research and find out more about this disease. The more research they do, the closer we'll be to having a cure one day. And it's a gift for all the individuals who currently have MS and in the future may be diagnosed.

It's not a gift of life, but it could be seen that way. One day when there's a cure, my family and I will know that my brother, Steven Rubin, was a part of it.

Editor's Note: The National MS Society supports MS tissue banks, which are storage facilities that provide brain and spinal cord tissues to researchers studying multiple sclerosis. [Learn more on the website.](#)