

REP. KEVIN HERN (OK-01): SPINDA BIFIDA

450 words max – 3 minutes

Thank you, Chairwoman DeLauro and Ranking Member Cole, from the great state of Oklahoma, for allowing me to testify before your Subcommittee today.

I'm here today to highlight the importance of research and development for a disease that is very near and dear to my heart. Spina Bifida affects about 166,000 individuals in the US, and over half are adults.

It is a birth defect for which there is no cure. It results in a spinal cord injury before a baby is born. Spina Bifida is the most complex commonly occurring, permanently disabling birth defect that is compatible with life. Unfortunately, much is still unknown about this disease.

Let me tell you a little bit about my experiences to explain why funding for this disease is so important to me. My mother lives with Spina Bifida. My parents experienced their first loss of a child when my oldest sister died of Spina Bifida shortly after birth.

My younger sister also has Spina Bifida and when she was pregnant, she was told that her daughter would also have Spina Bifida. She chose life anyway. Her daughter, my niece, was born and has spent her entire life in a wheelchair.

Even in a wheelchair, my niece was able to get pregnant and gave life to our beautiful and healthy great-nephew, Daniel, who is now 9 years old and a testament to why we should never give up on life. Every single life has value and purpose.

Unfortunately, funding for Spina Bifida is limited. The only place in the federal government that is specifically studying this complex condition for children and adults is the Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC through the National Spina Bifida Patient Registry (NSBPR) and the Spina Bifida Collaborative Care Network.

For all the individuals living with Spina Bifida, I support you. And I support increased funding for the Spina Bifida Program.

I appreciate the opportunity to testify before the Appropriations' Labor, Health and Human Services, Education, and Related Agencies Subcommittee today and I yield back.