



Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 2706/S. 1183)

On July 27th, 2023, Congresswoman Kat Cammack (R - FL) and Congresswoman Debbie Dingell (D - MI), in coordination with the National Down Syndrome Society (NDSS) hosted a Congressional briefing on the Charlotte Woodward Organ Transplant Discrimination Prevention Act.

Highlights from the briefing include:

Member Remarks

Opening remarks were shared by Congresswoman Cathy McMorris Rodgers (R - WA), Chairwoman of the House Energy and Commerce Committee.



Remarks were shared by Congresswoman Kat Cammack (R - FL).

Bobbi Sarmiento (panelist) and Josh Sarmiento with Congresswoman Kat Cammack (R - FL) and Congresswoman Debbie Dingell (D - MI).





Legislative Briefing

- The **Americans with Disabilities Act (ADA)** and **Section 504** of the Rehabilitation Act prohibits organ transplant centers from discriminating on the basis of disability, however, discrimination persists.
- A **2019 National Council on Disability (NCD) report** found the following:
 - **Healthcare provider bias** negatively affects transplant outcomes for people with disabilities.
 - People with disabilities, especially intellectual disabilities, have been denied access to organs because of **subjective judgments** about the value and quality of life with a disability and **misconceptions** about their ability to comply with post-operative care.
 - Some transplant programs have **categorical exclusions** based on disability and will not evaluate a person's medical suitability for an organ transplant because of their disability.
 - **52%** of people with disabilities who requested a referral to an organ transplant received a referral.
 - **35%** of those with disabilities "for whom a transplant had been suggested" never received an evaluation.
 - **43%** of pediatric transplant centers always or usually consider intellectual disabilities an absolute or relative contraindication to transplant.
 - **60%** of transplant centers report having serious reservations about giving an organ to someone with a mild to moderate intellectual disability.
- The **Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 2706/S. 1183)** seeks to end this type of discrimination by:
 - **Building upon rights and protections** established under the ADA.
 - Prohibiting covered entities from determining that an individual is ineligible to receive a transplant, denying an organ transplant or related service, refusing to refer the individual to an organ transplant center, or refusing to place an individual on a waiting list **based solely on the fact that the individual has a disability**.
 - Providing access to **expedited review of claims of discrimination** through the Office of Civil Rights (OCR) at the Department of Health and Human Services (HHS) and in a federal district court.
 - Does not compel providers to give preferential treatment to patients with disabilities but instead to use an **individualized, patient-centered approach** to ensuring patients with disabilities have equal access to the organ transplant system.
- **Important details** about the bill:
 - No fiscal impact
 - Bipartisan support in both chambers
 - Supported by a growing list of disability and medical organizations



Panelist Testimony

Charlotte Woodward, NDSS Education Program Associate

Hello!

My name is Charlotte Woodward and I am the Education Program Associate at the National Down Syndrome Society. It is an honor to speak to you today. I was born on December 18th, 1989, with Down syndrome and a congenital heart defect. Approximately 50% of babies born with Down syndrome are born with congenital heart defects. I had three open-heart surgeries when I was a baby, and a fourth open-heart surgery when I was ten years old [as doctors attempted to correct my condition]. As I continued to grow, however, there were signs that my heart was not keeping up with my body. I began to experience low cardiac-output syncope, which means that I would faint and collapse. My parents were told that these episodes would increase in frequency and that, without intervention, I would not live much longer. Unfortunately, my doctors determined that there were no further surgical options available to improve my heart function, and that I was in urgent need of a heart transplant.



On January 30th, 2012, my doctors performed a life-saving heart transplant during which I received a healthy new heart. I have been in excellent health ever since, and I am so very, very grateful for the generosity of my heart donor and my donor's family, and for the willingness of my medical team to provide me with the opportunity to receive this lifesaving gift!

Many people - including those with Down syndrome and other intellectual and developmental disabilities - need organ transplants, for various reasons. The problem is that more people need organ transplants than there are available organs. This means that doctors and transplant teams must make decisions about who will be given the opportunity to have a lifesaving organ transplant.

Doctors and transplant teams have discretion about whom they refer and approve for organ transplantation. Sometimes, because of myths, misconceptions, low expectations, stereotypes and biases, doctors don't refer people with intellectual and developmental disabilities to transplant programs, and sometimes transplant teams don't approve people with intellectual and developmental disabilities for transplants.

I was very fortunate - my doctors and my transplant team looked beyond my diagnosis of Down syndrome and I had a successful transplant. I have since gone on to have a very fulfilling life, which includes working at the National Down Syndrome Society and graduating in May of last year from George Mason University with a degree in Sociology with a concentration in Inequality and Social Change, summa cum laude.



When I began working at the National Down Syndrome Society I learned that not everyone is as fortunate as I was, and that people with Down syndrome were being denied life-saving organ transplants because of their diagnosis of intellectual and developmental disability. This is wrong!

I want to ensure that all people with disabilities who are in need of an organ transplant are given the same opportunity and access to organ transplantation that I had and that they are not denied organ transplants based on their disability diagnosis. This is why I am so passionate about the proposed legislation that bears my name: The Charlotte Woodward Organ Transplant Discrimination Prevention Act!

My colleagues at the National Down Syndrome Society and I believe in equal access to health care for all people, including those with Down syndrome and other disabilities. My bill would require doctors and transplant teams to give equal consideration to people with Down syndrome and those with other disabilities who are in need of organ transplants.

Please, I urge you, do the right thing and pass this very important legislation!

Panelist Testimony

Bobbi Sarmiento, Advocate

Good morning, everyone. My name is Bobbi Sarmiento and I am a wife, mother, and advocate from Ocala, FL.

While Charlotte Woodward is a beautiful example of someone who has received a heart transplant, we are the story people want to pretend doesn't happen. I wish we were telling a success story. Unfortunately, we are not.

We learned at 10 weeks gestation that our son, Zion, had Down syndrome and at his 20-week anatomy scan that he had a heart defect called a complete AVSD or also called a complete AV Canal Defect. Simply put, we have 4 chambers in our heart. Zion had a large hole in the center separating those chambers from forming. This is a common heart defect those with Down syndrome have.

Our beautiful boy was born June 15, 2021. We spent 40 days in the NICU before being discharged to go home. We have some of the best memories of our time at home before his open-heart surgery was scheduled for September 20, 2021. We did all the research and asked all the questions. We never knew we would end up being the worst-case scenario.

To make a long story short, Zion had 5 open heart surgeries in a matter of 12 days. He was such a warrior through each one. After the 5th surgery didn't work as planned, we were told he would need a heart transplant. The hospital we were at did not do transplants and we had 3 options in Florida. To qualify, we were told his other organs had to be working, which they were, and I have the autopsy to prove this.





Our first option told us that they had never done a successful heart transplant on someone with Down syndrome. I asked how many they have tried. No response. Through my own research and digging that moms do to get answers, I have since learned that answer was 0. Our second option said they didn't feel their team could do a successful heart transplant for Zion. The third option kept us waiting. They came back and said because Zion was on ECMO life support 3x through the 5 surgeries, he couldn't have brain activity. I would like to note that Zion came off ECMO after the 2nd and 5th surgery – which we knew upfront was vital to being accepted for the heart transplant list. They wanted a brain activity test run and sent to them for their final decision. We were told before it was sent that the test was perfect. With nothing to disqualify him, we thought we would be on our way to the next step. They came back and told us that after much deliberation, they concluded that they just couldn't waste a heart. Our son was worth the same chance at life as anyone else. With no options left, we had to make the decision to remove the machines. On October 8, 2021 our son left my arms and ran into the arms of Jesus.

We are now taking our pain and finding purpose. Zion's Army started as a way give people updates and to ask for prayer for Zion. We never dreamed his story would reach over 38 million people. Zion's life is now our mission. At Zion's Army we Celebrate Life with those who have Down syndrome sending gifts to those having their 1st birthday. We didn't get to celebrate Zion's 1st birthday with him, but we know they are so WORTH celebrating! We Honor Child Loss and stand with parents through helping make funeral arrangements and remembering their child in various ways throughout the year. We are all Down syndrome advocates. My husband, my son, and all of Zion's Army will forever shout the worth of those with Down syndrome and bring awareness to the issues we were never aware of before we were blessed with Zion. And lastly, we raise funds for CHD Research through a yearly CrossFit event. Since we are proof that things like this do happen, we support research to help save lives.

We need your support for the Charlotte Woodward Organ Transplant Discrimination Prevention Act. This bill would not only clarify that the type of discrimination Zion faced is in fact discrimination, but it would also create a process in which individuals with disabilities and their families can get the relief they deserve. The goal of the bill is to ensure that if an individual is discriminated against based on their disability, the discrimination can be corrected, and a life can be saved.

No other parents should be standing here wearing their son's ashes telling his story. Zion's life was worth it and so are others with Down syndrome. We are not asking for special treatment, just the same chance at life as everyone else. Thank you.





Panelist Testimony

Dr. Mary Stephens, MD, MPH, FAAFP, FAADM

My name is Mary Stephens. I am a family physician with over 25 years' experience in patient care and teaching. I am also Callie's mom and am very honored to be here speaking to you all today. I'd like to talk about 2 things, ableism and diagnostic overshadowing, and how these two issues play a role in the discrimination that individuals with disabilities face all too often in the organ transplant system.

Let's talk about ableism – Ableism is the belief that people with disabilities have lesser value than their nondisabled peers. I'd like to share John's story.

John was born about 30 years ago. In the months following his birth, his mother had suspicions that he may have Down syndrome but doctors disagreed, and they were told he just looked like his father. Ultimately, a geneticist confirmed that John did in fact have Down syndrome and suddenly John's parents were given a very grim outlook. They were told it was unlikely that he would ever be potty trained and that he would have significant issues with executive function such as if he was outside and it started to rain, he wouldn't know to come in out of the rain. John's parents were devastated by this ableist prognosis, but with John's twin brother and another child at home, they decided to raise all 3 kids with the same expectations.

Today, John is thriving. He lives just outside Philadelphia with his parents and dog. He completed a 3 year "Post High School Transition Program" in Massachusetts where he gained "social, vocational, and independent living skills". He became very independent during that time, even traveling back and forth between Massachusetts and Pennsylvania on his own for breaks. He works 20 hours a week at a local grocery store and he loves bike riding. He participates on Special Olympics basketball, volleyball, and floor hockey teams and loves going away for long weekend programs. Recently, John told us with a smile on his face that he had a great life.

John's experience is an interesting one to think about in the context of organ transplant discrimination. When John's doctors thought John just "looked like his dad," he was met with positive attitudes and proactive levels of care, as opposed to the vastly different attitudes and levels of care he received when his official diagnosis of Down syndrome was given. John, like the over 50% of individuals with Down syndrome who are born with congenital heart defects, can need an organ transplant one day. This begs the question – if John needed a heart transplant and had never received a diagnosis of Down syndrome, despite the fact that he genetically does have Down syndrome, would he be discriminated against? Hearing stories like baby Zion's, and the fact that Zion's parents were told by doctors that they "just couldn't waste a heart" makes it clear that ableism still plays a major role in the attitudes and level of care that healthcare providers administer today, over 30 years after John's birth and diagnosis.





The Charlotte Woodward Organ Transplant Discrimination Prevention Act seeks to prevent both willful and unintended discrimination against people with disabilities. Willful discrimination, largely attributed to the ableist views that providers and systems hold, continues to be a pervasive threat to the quality of life and access to care that individuals with disabilities need and deserve.

I would now like to touch on the unintended discrimination that this bill seeks to eliminate. This type of discrimination is more complex as I really do believe that the majority of physicians and healthcare providers act in good faith to care for their patients. However, too often an event called diagnostic overshadowing impacts the quality of care that individuals with disabilities receive.

Diagnostic overshadowing is a harm that extends from a cognitive bias and contributes to health care disparities. In patients with disabilities, symptoms and signs are attributed to the disability and further investigation is prematurely halted. In the simplest terms, patients are dismissed as just “having Down syndrome” or another disability, instead of being given the patient-centered, specialized care that they need. The Joint Commission, a global driver of quality improvement and patient safety in health care, has called this phenomenon a sentinel event.

I didn’t really “get it” if you will, until my daughter Callie who is now 12 (and who happens to have Down syndrome) suddenly developed recurrent episodes of difficulty breathing after coming down with the croup at 6 months of age. My husband and I, both family physicians, struggled to find the right answers to understand what was wrong with her. We realized when we were told, “Well you know she has Down syndrome”, she was in trouble! Fortunately, we found the right team for Callie and things turned around by her first birthday. She’s now entering 7th grade in an inclusive educational setting and appeared in High School Musical Junior this year and swam with a dolphin!

I have now focused my professional career on providing care to individuals with complex childhood-onset medical conditions. When I’m teaching a new group of students or residents, I will often start the lecture by asking them what are the causes, in a previously healthy full term 6 month infant, of recurrent respiratory distress after an episode of croup. They hone in on Callie’s diagnosis pretty quickly. It’s ironic, Down syndrome never comes up in the conversation. When I tell them she has Down syndrome after doing that exercise and discuss the dangers of diagnostic overshadowing, their responses are more nuanced and include issues related to Down syndrome but they never say the answer is Down syndrome. They get an A – and hopefully think harder when they care for a patient with a disability in the future.

This very personal experience with my daughter not only opened my eyes to the dangers of diagnostic overshadowing but I think is an important illustration of how this phenomenon can lead to unintended discrimination against people with disabilities. Such is the case too often in the organ transplant system. Bobbi shared how the first and second transplant options in their state attested that they had “never done a successful transplant on someone with Down syndrome” and that “their team didn’t feel they could do a successful transplant on a patient with Down syndrome.” These categorical claims based on the patient’s disability alone go to show that diagnostic overshadowing can and does play a major role in perhaps unintended discrimination against people with disabilities.



We have work to do in how we approach the care of people with disabilities. It's important that our care is patient-centered and that we practice shared decision making. It's important that in patients facing the need for organ transplantation, the health care team looks at the whole person and doesn't stop thinking once they hear that the patient has Down syndrome.

The Charlotte Woodward Organ Transplant Discrimination Prevention Act works to eliminate this unintended discrimination by calling out specific instances in which discrimination may be present, such as in determinations around post-operative care, and creating a mechanism in which individuals and families can receive the timely and lifesaving care they need. The goal is not to punish, litigate, or denounce healthcare providers but instead to ensure that patients with disabilities can access an organ transplant system, and a larger healthcare system, that is free from discrimination.

In conclusion, there is clearly work that needs to be done to ensure that individuals with disabilities are receiving nondiscriminatory care. And it does not just stop at the organ transplant system. We know that people with Down syndrome and other intellectual disabilities still face unnecessary challenges. My colleague Dr. Brian Chicoine, shares in this piece how he was challenged when one of his patients with Down syndrome ended up in an ICU due to Covid-19.

Despite the fact that the patient was steadily improving, he was constantly challenged to make her DNR, seemingly based on the simple fact that she had Down syndrome. Colleagues and I have recently submitted an article looking at the odds of being given a DNR order if you have a diagnosis of Down syndrome. I'll spare you the statistics, but the odds of being made DNR based on the diagnosis of Down syndrome are 6 times greater when controlling for other factors. 6 times.

While we obviously may not be able to solve all of the problems our healthcare system faces in this bill, we do have the opportunity to correct one type of injustice and ensure that no family has to hear the words and experience the type of dismissal and ableism that Zion's family faced. **As a medical expert with over 25 years of experience and as a mother, I strongly support the Charlotte Woodward Organ Transplant Discrimination Prevention Act and urge Congress to take action on this important bill.** Thank you for your time today.



For more information, please contact Anna Fedewa, National Down Syndrome Society Manager of Federal Government Relations, at afedewa@ndss.org