



Hello, my name is Stacey. This is my daughter Charlee and the rest of my family, we are from Pittsburgh, Pennsylvania and we came to Washington DC for our first time ever, to share with you Charlee's story and how multiple imaging technologies have enabled us to be here today. This is new for me, I have never spoken in this public of a forum before, but I thank you all for being here and for listening, this is important.

You see Charlee is holding a personalized 3D-printed model of her kidney. This technology and the imaging that brought us to this point is why we are here tonight.

Charlee started having some bowel issues in December of 2017. After two days of assuming she had some gas in her stool, her pain increased, and we ended up with an ultrasound and a CT scan which identified a Wilms tumor in Charlee's kidney. Wilms is a childhood cancer which begins in the kidneys.

Our Charlee was diagnosed with stage 5 cancer, at age 4.

Charlee went through multiple rounds of weekly chemo treatments prior to surgery, a horrible experience for anyone to go through, but particularly awful when it is your child and you feel helpless as a parent and confused about what is going on despite your best efforts to comprehend the enormity of it all.

CT scans can find tumors, and they can also show you if the tumor is shrinking. Charlee's tumor was reacting so well to the chemo that they decided to do six more rounds of chemo before operating on her. The tumor did not go down as much with the next six rounds.

In April 2018, Charlee was admitted for surgery. Charlee's surgeon, Dr Austin came into talk to me about what was going to happen in the surgery room.

This was, as you can imagine, a terrifying time for us as a family, and in those uncertain moments you appreciate really any sort of certainty or comfort as you face the unknown.

It was at this time when Charlee's surgeon brought us the personalized 3D print of Charlee's kidneys. Charlee and I were able to see exactly where her cancer was, what it looked like, and how they planned to remove it. Holding this imaging model in our hands really put everything into perspective for us and we know that is also assisted her surgeon in planning her surgery.

Radiologists made this model from her CT scans using a special 3D printer that uses a laser to make a life-size model from liquid plastic. This technology allows the Radiologists to put Charlee's imaging in our hands. .

When you wonder how federal investment into medical technology impacts patients, this is one of those examples I hope you remember. It not only helped us, but Charlee's entire surgical team. This model provided us with knowledge and a new level of understanding, and it made her surgery safer.

In April of last year, Charlee went in for a 10-hour surgery that kept her in the hospital for 12 days, home for 2 days and back for 7 days of radiation. They were not able to save her left kidney, but her right kidney is doing great and I know the imaging and 3D printed model is a big reason why.

Charlee has relied on CT scans to diagnose her, to determine the effect of the chemo on her tumor, to create a personalized print of her kidney and finally to continually show us that Charlee is and we hope remains cancer free!!! Charlee had her port removed this January and boy was she excited. As we look ahead we will continue to rely on CT scans, Ultrasounds and chest x-rays to ensure she stays healthy.

I never thought of myself as a patient advocate, but when I was asked to share my story, I was happy to do so, because these technologies made a difference for us, and we hope they will continue to help others. Thank you all for being here tonight.