

Lisa Schaffner: The UNOS Advocate - Working Together to Save Lives
by Lezlee Peterzell-Bellanich, author of upcoming book *Saved by a Stranger* and UNOS Ambassador
Below is from an interview with Lisa in July 2020

“UNOS stands for United Network of Organ Sharing - not UNO Pizzeria,” Lisa laughed. As the Public Relations and Marketing Director for UNOS, she likes to describe it as “You and Me Working Together Saving Lives through Organ Donation and Transplantation. UNOS (you and me). It helps people remember and phonetically pronounce it correctly.”

What is UNOS? UNOS is the private, non-profit organization that serves as the nation’s organ transplant system which is called Organ Procurement Transplantation Network (OPTN). The OPTN is operated under contract with the U.S. Dept. of Health and Human Services by the United Network for Organ Sharing (UNOS). Therefore, this is a unique private-public partnership that links all professionals involved in the U.S. donation and transplantation system. Headquartered in Richmond, VA, there are over 400 team members ranging from researchers to policy developers. UNOS does sight surveys to ensure that transplant centers are following policy.

“We are the Mama Bear in the middle,” Lisa described. “On one side there are 58 Organ Procurement Organizations in the country and that’s the donor side. They work closely with families when there is an imminent death in an ICU setting in a hospital. That information gets put into our computer system (UNet, within called DonorNet). Then we are able to make the match happen with more than 110,000 people on the organ recipient transplant waitlist via the transplant hospitals in the United States. With Mama Bear being in the middle, organ “offers” go out to Transplant Coordinators at hospitals where the transplant surgery takes place.”

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In 2019, UNOS was central and vital to the coordination of 39,718 transplants. It was the 7th consecutive year in a row where the number of transplants increased from the previous year. In March and April of 2020, at the height of Covid, the transplant numbers were down 50% but they have since bounced back. Living donation came to an almost complete halt because the living donor, who is well, would be entering into a hospital environment during a pandemic, which was too risky.

As a former reporter, Broadcast Journalist and TV Anchor for over a 30-year span in Green Bay, WI and Richmond VA, Lisa understands the importance of tag lines to remember important information. “I was the Blonde Anchor you saw on the evening news,” she joked. She loved Broadcast journalism but when her two children were entering High School and Middle School, she made the decision that “it was time for this mother to be at home with her children and not sitting at the anchor desk at 11: 00p.m talking to people that you cannot even see.” What was tricky for Lisa was that she wanted to find a career that she was equally passionate about since she truly loved broadcast journalism.

“Welcome to UNOS where I get to meet people who share their incredible stories and we have life altering conversations. It has been amazing and changed my world!” she beamed.

“Like many of us, at the age of 16yrs old, when I registered to get my driver’s license, I became aware of organ donation and became a registered donor. In 1984, the Spring Quarter of my last semester in College, I was invited to take a class with the Dean of Communication on Persuasive

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Speech Making. We all had to pick a topic, and of all things I chose “Organ Donation.” Fast forward to the Fall of 2008, I began working as the PR/Marketing Director at UNOS. The Executive Director of UNOS at that time pulled me into his office and we talked about the fact that UNOS was created on March 21st, 1984. The realization of this personal coincidence hit me like a thunderbolt. In March of 1984, while I was a Senior at Ohio University in the College of Communication doing this persuasive speaking class on organ donation that helped to support transplantation, UNOS was actually being formed. It was a sign that I had come full circle, exactly where I was supposed to be and if I had any doubt, it was clear to me.”

“Back in the 80’s,” Lisa continued, “transplants were happening but they were experimental surgeries. When I was a young reporter in 1986 in Richmond, VA, I was covering a young 6yr old child who needed a heart transplant. Health insurance did not cover transplants at that time and the family had to raise the full amount before the surgery could take place. That is how far we have come since then.”

“Before UNOS,” Lisa continued, “there were groups performing transplants centered around teaching facilities. In different pockets of the country, the donors would have to be in the same hospital as the recipients or close by. It was a combination of living and deceased donation.”

On October 19th, 1984, the Congress of the United States approved the National Organ Transplant Act (NOTA) which established the framework for the U.S. organ transplant system. Before NOTA was put in place, there was no clear jurisdiction on what property rights were for a

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human corpse. Due to a shortage in organs but a growing demand for transplantations, people began to use other means to purchase organs outside of a hospital setting. The organ market began to become a commercial market. NOTA outlawed the sale of human organs and provided for the establishment of the Task Force on Organ Transplantation; authorized the Department of Health and Human Services to make grants for the planning, establishment, and initial operation of qualified Organ Procurement Organizations (OPOs); and established the formation of the Organ Procurement and Transplantation Network (OPTN). UNOS won the contract to operate the entire transplant system for the United States. They have been doing it ever since.

Initially, UNOS did not have the powerful computer matching system that it does today. Today they have UNet which is an online database system that collects, stores, analyzes, and publishes all OPTN data on potential donors and patients on the UNOS waiting list. The OPTN tracks and has tracked every organ donation and transplant event occurring in the United States since October 1, 1987.

Imagine in the 1980's, a room full of telephone operators trying to match donors with recipients. Today, data about a potential donor can be immediately uploaded into the UNet system by Organ Procurement Coordinators (OPC's) which then give out "offers" to Organ Transplant Coordinators who are looking for matches for their recipients.

With the development of immunosuppressant drugs, the rejection of donor organs is more controlled. Without the advent and access to proper drugs after transplant, the recipient would

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reject the organ as a “foreign entity”.

“When I go out to talk to people,” Lisa said, “so often the transplant is the end goal because you want to get to a successful transplant. But truly, for most transplant recipients, that is just the beginning. After transplant, it becomes about staying and remaining healthy.”

“Every April is *National Donate Life* month where we talk about the importance of Organ Donation and Transplantation as a nation. Recently, in one of my talks, I spoke with a woman who had had a heart transplant when she was 2 years old and she is now 28yrs old. I asked her if she was frightened by the pandemic and keeping herself safe so that she would not pick up Covid-19. She said, “No. I am not any more scared than I was as a little girl when I first got my transplant. You all are now living my world. This is how I have always lived. When you have a transplant, you have to be aware of the people around you and stay at a distance from anyone who has symptoms of being sick, asking if they have a temperature before you meet face to face. You need to wear a mask in public so you don’t pick up other germs and wash your hands often. The rest of the world is now experiencing my life!” The new reality that with Covid, we are now living the regular life of organ transplant recipients.”

“The most difficult challenge is deciding who gets the organ and who doesn’t. There are many more people on the waiting list than available viable organs,” Lisa stated. “We have to decide through various allocation policies who gets it and when. UNOS includes a large group of researchers and educated volunteers in the transplant community and from the general public

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who are on different committees which help shape policy. Everyone needs to have a voice in how policy is created. We try and be very transparent to promote how people can get involved. We encourage people to participate in "Public Comment" which happens every Spring and Fall where there are a variety of different policies that we want input from the general public before enacting them. All of this is on our website."

"We are moving into continuous distribution by expanding the donor network. There are different numbers of registered donors in certain regions of the country which affects the donor pool. Right now, where you live determines how quickly you get a transplant and that is not fair or equitable so we are trying to change this policy to level that playing field a little bit more."

Lisa explained.

"I have to admit, before I was working for UNOS, I assumed that when I die, because I am a registered organ donor, I will automatically be a donor. But it doesn't work like that. You have to die within a medical setting so that blood and oxygen are being pumped to those organs to keep them viable for transplant and then pronounced legally brain dead with no chance of recovery. In other words, if I happen to die in a car accident on I95 later today and then I am pronounced dead on the scene, it doesn't matter whether I wanted to be an organ donor or not. My organs are not viable for transplant if I am dead. I could still donate skin, bone, or tendon, but not a life-saving organ."

"UNOS keeps an eye on technology that will improve the quality of organs through Profusion

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Organ Preservation Systems and even drone technology to transport organs to transplant hospitals more efficiently. In April of 2019, the first kidney was transported by drone to a transplant center in Baltimore. Back in the '70's, people had OMG conversations that are happening now. If we can imagine it today, we can make it happen in the future.”

By working with the public educating them about Organ Transplantation and the important role UNOS has in making this happen, Lisa has been able to tap into her creativity as well.

“We have a wonderful art gallery at UNOS at our main headquarters in Richmond, Virginia where art is displayed as part of education. As you are inspired by the art here on the wall, may you also be inspired by our mission to save lives through transplantation,” Lisa smiled.

“Many people may wonder what art has to do with transplantation. When you hear recipients talk about their transplant, they have a new lease on life and have been transformed. And as a person who takes in art, it connects and inspires you. We have found this to be a great vehicle of expression. The past and present exhibitions are all on our website. Our current exhibition is called “Art of the Scar: Redux (because it is the second time doing this).”

“In 2014 we worked with a group of High Schoolers in a photography club. We took these 34 students, divided them into two groups, and teamed them with living donors and transplant recipients, both of whom have scars. While most of us try to cover up our scars, people in the transplant world proudly want to show you their scar as a badge of honor. The teams learned

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about each person, took pictures, and then turned it into whatever type of art they wanted. We came up with 35 original works of art. Seventeen pieces are on a traveling exhibition which go to transplant centers and organ procurement organizations to tell the story of UNOS through Scars. Because of Covid, we thought it was better to bring a lot of the pieces back to the UNOS building which is not closed.”

In addition, Lisa created a community volunteer program where a person can become a UNOS Ambassador promoting organ donation. “We have 1800 Ambassadors who have sought out UNOS and want to give back. What we ask of Ambassadors is that they advocate on behalf of UNOS, educating the public on what we do, and help us shape policy so that as many people as possible can get transplanted. Give your input because we want to make it more equitable. We also ask UNOS Ambassadors to share stories on social media because stories make a difference.”

Personal Note from this author:

As a caregiver, advocate, and author of *Saved by a Stranger* published in the Fall of 2021, I am devastated by the news of the passing of Lisa Schaffner. While this chapter did not make the final edit of my upcoming book, I wanted to share it because it gives insight into her background and work on behalf of UNOS. I included her in my book acknowledgments because she provided such important information and encouragement just before my husband’s liver transplant.

After my online petition asking UNOS to consider allowing exception points on MELD scores for liver transplant patients with primary sclerosing cholangitis, Lisa reached out to me personally, connected me with her colleagues at UNOS, encouraged hundreds of us to write on the public comment section of the UNOS website - all of which led to an important policy change on behalf of PSC patients. Lisa was passionate about her work, positive, warm, and made a difference in so many people’s lives. In her honor, I will become even more committed as a UNOS Ambassador.