

WALKING THE RUNWAY TO REVEAL THE BEAUTY OF TRANSPLANTATION



PHOTO BY IRYNA SHOSTAK



LEFT: Valen models her 60 inches of scars at New York City's DreamWalk, a fashion show that gives people who have overcome challenges an opportunity to tell their stories and inspire others. Today, Valen is a patient advocate for polycystic kidney disease and organ donation.

A double transplant patient takes to the fashion runway to show others the journey can be transformative.

Written by Gail Appleson

Valen Keefer could easily be mistaken for an actress, a network television anchor, or even a model. Strikingly beautiful, she exudes self-confidence, intelligence and charm.

In fact, Valen, 37, walked the runway of a New York City fashion show just last year. Although she was stunning, that wasn't why she won this coveted spot. Instead, Valen was selected because of her courage and spirit during a lifetime of serious illness that resulted in two transplants. Her outfit was specifically designed to display Valen's 60 inches of scars, which were highlighted with glitter. The fashion show, DreamWalk, gives people who have overcome challenges an opportunity to provide inspiration through their stories. Valen says she took to the runway to encourage others to embrace their journeys and find beauty in their own personal scars.

Valen has spent most of her life as a patient at various hospitals. She has epilepsy and severe scoliosis, which required back surgery when she was young and again as an adult. But her most trying health challenges came as a result of polycystic kidney disease (PKD), which she inherited from her mother's side of the family. She was diagnosed with PKD when she was 10 and at the time, no family member with the disease had lived past the age of 53.

When she was a teenager, both of her kidneys were removed and Valen was hospitalized for almost a year. She was on dialysis, endured severe pancreatitis, and received more than 70 blood transfusions. At age 19, she received a life-saving kidney transplant from a living donor.

In her early 30s, PKD affected her liver and she became seriously ill. Valen received a liver transplant at age 35, which restored her health and the ability to do what she loves: helping others and living life to the fullest. She has turned her health challenges into something meaningful and become the role model she wished she would have had when she was younger.

Now, a patient advocate for PKD and organ donation with her own website, valenkeefer.com, Valen has appeared at about 100 events across America encouraging and supporting all types of audiences. The fact she looks great is an important part of her story.

"It's important for others facing chronic illnesses and heading into transplant to see a healthy person in front of them—a person who has endured and overcome what they are about to experience," she says. "I want them to know and see that there is a beautiful and joyful life post transplant, that they can do it too and that life is worth fighting for."



PHOTOS COURTESY OF VALEN KEEFER

ABOVE: (left to right) Valen with husband, Noah, at the Gateway Arch a few days before her transplant; with Jeffrey Crippin, MD, during her nine-month transplant follow-up exam; waking up to Noah after her liver transplant.

RIGHT: Valen Keefer and her physicians, William Chapman, MD, (far left) and Jeffrey Crippin, MD (second from the right), were speakers at the Garden of Life Gala, which was held earlier this year to celebrate 10,000 transplants at the Washington University School of Medicine and Barnes-Jewish Transplant Center. Mid-America Transplant was honored at the event with the Innovation and Leadership Award.

"I find that this is the reason why I survived all of this. It gives a purpose to the pain," she says. "Even though my life has been super hard at times, this is the deep-rooted purpose that keeps me grounded in gratitude. Being grounded in gratitude is really the foundation of me."

Valen's positive attitude and determination have helped her achieve what she calls an amazing life. She met her soul mate, Noah, in 2007, and they married on Sept. 17, 2011. Things were going well for the couple, who live in northern California, until 2016. It was then that Valen began to suffer recurrent episodes of infections to the point she developed a life-threatening antibiotic resistant bacterial infection. Finally, in 2018 her doctor in California said Valen needed a liver transplant or she would die. To improve the chances of getting an organ sooner, the doctor suggested that Valen dual list in California and another state. The physician's top recommendation was the Washington University and Barnes-Jewish Transplant Center in St. Louis.

However, following the doctor's advice meant the couple would have to temporarily relocate to St. Louis. It was a tough decision because it meant traveling far from the home they loved in northern California.

But after Valen was evaluated at Barnes-Jewish, they knew it was the right choice. Valen believes she is alive today because of her surgeon, William Chapman, MD, chief of the Section of Transplant Surgery, division chief of General Surgery at Washington University School of Medicine, and hepatologist Jeffrey Crippin, MD, vice chairman for Clinical Programs in the Department of Medicine.

"I only had to wait one week for a liver. That was extraordinary," Valen says. "Six weeks later I couldn't believe I was walking in an airport and on a plane on the way home."

Although Valen was a complicated case, Dr. Chapman explains that the surgery went smoothly because the center has extensive experience transplanting patients with complex medical problems that some hospitals and physicians don't have the expertise to address.

"The top tier medical and surgical care combined with the collegiality of the entire team makes this a place that patients want to come," says Dr. Chapman. "It's a multidisciplinary team. That's a catchy term today. But I will tell you that in the area of transplant, we were doing it well before anyone else was doing it. We've been using that approach essentially since transplant started."

The transplant teams comprises professionals from a variety of disciplines. They include surgeons, hepatologists, nurses, coordinators, anesthesiologists, social workers, dieticians and financial counselors. The team may expand to include other specialists, such as oncologists, when needed.

Dr. Chapman notes that some of the center's coordinators have been at the transplant center for more than 25 years and are available 24/7. "Because of that, patients are able to develop a lifeline to the program. It's very reassuring to the patients," he says.

Valen agrees, adding that a year after her liver transplant, she had the option to switch her care to California doctors near her home.

"There is no way I would ever do that. I have no interest in switching because I have such trust in Barnes-Jewish Hospital," she says. "I know I'm where I ought to be. Being able to have trust in who cares for you is priceless. It's huge in a patient's world to know that if something happens you have this extraordinary team caring for you. It gives you hope that no matter what, everything will be ok."

Valen says she will be eternally grateful to Drs. Chapman and Crippin.

"They are both so caring and genuine. You can just feel that their work is not what they do. It's who they are," she says. "I am thriving today because of them, my donor and the entire health care team at Barnes-Jewish Hospital." ✨

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— Valen Keefer



PHOTO BY THOMAS MICHAEL

CELEBRATING

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DRS. CHAPMAN AND CRIPPIN RECEIVE PRESIDENT'S ACHIEVEMENT AWARD FOR TRANSPLANT WORK

PHOTO BY TIM PARKER

To ensure that more patients like Valen Keefer benefit from the expertise of top physicians, The Foundation for Barnes-Jewish Hospital established the President's Achievement Award to recognize physicians who partner with the Foundation to uphold its mission and support the strategic framework of Barnes-Jewish Hospital. Although the award has traditionally been given to one recipient, this year there are two: William Chapman, MD, chief of the Section of Transplant Surgery, division chief of General Surgery at Washington University School of Medicine and hepatologist Jeffrey Crippin, MD, vice chairman for Clinical Programs in the Department of Medicine.

Dr. Chapman is the Eugene M. Bricker Chair of Surgery at Barnes-Jewish Hospital and Washington University School of Medicine. The endowed chair was established by the Foundation in memory of Eugene M. Bricker, MD, a renowned surgeon and professor of surgery whose medical career at Barnes-Jewish and the School of Medicine spanned more than a half-century.

Dr. Crippin is The Foundation for Barnes-Jewish Hospital Marilyn E. Bornefeld Endowed Chair in Gastrointestinal Research and Treatment. The chair was established by the Foundation to honor the wishes of the late Marilyn Bornefeld, a Crohn's disease patient who was treated at Barnes-Jewish Hospital. Marilyn left her estate to the Foundation with the hope of helping others with Crohn's, a chronic disorder that causes painful and often debilitating inflammation of the digestive tract.

When speaking about this year's President's Award recipients, Timothy J. Eberlein, MD, FACS, chair of the Department of Surgery at Washington University School of Medicine and director, The Alvin J. Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine, says, "Will Chapman's leadership in transplantation has led to outstanding success in our Transplant Center. With this shared President's Award from The Foundation for Barnes-Jewish Hospital, Drs. Chapman and Crippin will continue to lead advancements in liver transplantation."

Boasting one of the preeminent transplant programs in the world, the Washington University and Barnes-Jewish Transplant Center's specialists are recognized as pioneers in the development of many surgical and medical innovations for treating patients with end-stage organ disease.

Dr. Crippin says that philanthropy has been crucial to the success of the transplant program.

"The generosity of donors provides us with resources that otherwise would not be available. These gifts can assist patients, physicians, trainees, nursing staff and the hospital in general. Donations can support research efforts allowing us to potentially make a difference in the life of a patient immediately or in the future," he says. "Many of the treatments we use today once started as an 'idea' that was subsequently tested. Those trials are crucial to transplant teams improving the care of patients and their outcomes."

One example is a recently completed trial aimed at increasing the number of viable organs for patients with liver failure. As with Valen Keefer, a successful transplant is the singular lifesaving option for these patients, but due to the limited availability of organs, many die while on the waiting list. In response to this critical shortage, the Washington University and Barnes-Jewish Transplant Center took the lead in a national trial testing discarded donated livers that received normothermic machine perfusion (NMP) compared with standard cold preservation. NMP permits extended preservation times with the ability to simultaneously perform liver viability assessment. It is believed that this technology will expand the availability of livers for transplantation that may currently be considered marginal, resulting in more access and improved transplant outcomes. The results are currently under review by the FDA.

"Marginal livers will benefit from being on that device and that is going to change the way we approach patients and will make more organs available," Dr. Chapman says. "Now about 20 percent of our patients die on the waiting list. We can't get an organ for them soon enough and that's a terrible problem for us nationally and locally. This strategy should help." ✨