

Heart Transplant Recipient Discovers A Calling for Advocacy, Support for Others

April 11, Prague, Czech Republic—Glen Kelley's journey as a heart transplant recipient came full circle today in Prague, as he addressed attendees of the Annual Meeting and Scientific Sessions of the International Society for Heart and Lung Transplantation (ISHLT), including members of his own care teams.

As a high school senior outside of Peoria, Illinois, Kelley was diagnosed with stage-4 Hodgkin's lymphoma and underwent eight months of chemotherapy and radiation. After 10 months in remission, the cancer returned, and he received a bone marrow transplant. With his cancer once again in remission, he finished college and went on to enjoy an extremely active life for the next 17 years, skiing, cycling, climbing mountains, and even running marathons.

Then out of nowhere, Kelley suffered a heart attack at 36. Doctors found his right coronary artery nearly completely blocked and placed three stents to prop it open. Over the next decade, his ailing heart would require more stents, valve replacements, and not one but two coronary artery bypasses at the University of Minnesota Medical Center in Minneapolis. By 2015, Kelley was in heart failure — most likely the result of the radiation he received in his teens.

He was placed on the transplant list and eventually transferred to Baylor University Medical Center in Dallas, where he received a new heart in 2016. An unusually long and rough recovery period followed, during which he suffered kidney failure, a fungal infection, and two bouts of organ rejection. In 2019, he received his second organ transplant, a kidney indirectly donated from his youngest son.

"I had support along the way from my physicians and healthcare providers to volunteers at the support group Second Chance for Life," said Kelley. "I don't think my outcomes would have been nearly as successful without the support I received throughout my journey."

Despite all his health problems, Kelley led a successful career in IT and marketing, including 17 years at IBM. But it was through his experiences as a patient that he realized his true calling.

"My metrics changed from how well I did at my day job to how many patients I could help," he said. "Patients became my currency."

Kelley dedicated himself to supporting patients dealing with advanced heart disease through in-person and phone visitation and support groups, ultimately serving as president of Second Chance for Life for four years. During his tenure, the group created an alliance with the international group Mending

Hearts, the world's the largest peer-to-peer heart patient support organization with 115,000+ members.

With Mended Hearts, Kelley had an opportunity to continue working in patient education and support — and to become more involved in advocacy and legislation at the state and federal levels. Today, he serves as the group's Patient Voice and Advocacy Leader.

"Working in advocacy allowed me to help not one but thousands of patients at a time," he said.

Today, Kelley fills his days with phone calls to patients, in-person visits, and advising. In his new role as Patient Advocate Trustee on ISHLT Foundation Board of Trustees, Kelley will help to ensure the Foundation agenda addresses issues that matter most to patients with advanced heart and lung disease.

His highest calling yet may be serving the United States' new Organ Procurement and Transplantation Network (OPTN). Created last fall by a bipartisan law, OPTN is charged with revamping the country's organ transplant system. Kelley was elected thoracic patient representative to OPTN's Board of Directors.

"Patients always need support, whether they know it or not, at some point in their journey," said Kelley. "This motivates me to do the work I do. I want to empower patients through support and education and teach them how to self-advocate."

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About ISHLT

<u>The International Society for Heart and Lung Transplantation</u> (ISHLT) is a not-for-profit, multidisciplinary, professional organization dedicated to improving the care of patients with advanced heart or lung disease through transplantation, mechanical support, and innovative therapies via research, education, and advocacy. ISHLT members focus on transplantation and a range of interventions and therapies related to advanced heart and lung disease.

The Annual Meeting and Scientific Sessions of the ISHLT will be held 10-13 April at the Prague Congress Centre in Prague, Czech Republic.

Contact:

Jess Burke, Director of Marketing and Communications +1.312.224.0015