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COLUMBUS MAN BECOMES PATIENT ADVOCATE AFTER HORRIFIC MEDICAL ERRORS *Kidneyless and 85% Sightless, His Fight is Just Beginning*

COLUMBUS, Ga.—Jay Adam Blum never planned to be a patient advocate. But when two devastating medical errors left him kidneyless and nearly blind, the choice was made for him.

Born in Philadelphia, Blum's work sent him to more than 19 countries, five U.S. states, four aircraft carriers, two submarines, and three Native American reservations before he settled down in Columbus with his wife and son. He was diagnosed with multiple cancers affecting his thyroid and both kidneys. Now chained to a dialysis machine to stay alive, Blum's health challenges were compounded by a stunning series of medical errors.

In 2011, Blum's primary care physician referred him to a urologist for trace amounts of blood in his urine. The urologist found a cancerous mass in his left kidney, and two days later, the kidney was removed entirely. In 2014, a mass in Blum's right kidney required further attention by an intervention radiologist. His previous doctor had left the practice, so Blum's new surgeon operated.

Two months after the ablation, the intervention radiologist claimed that he had underestimated the size of the tumor. He told Blum that he would need a second ablation surgery to remove the remaining tumor tissue. Two months after that procedure, the intervention radiologist claimed once again that he had not removed all the tumor tissue. This time during the ablation, unbeknownst to Blum, the intervention radiologist burned two holes through the wall of Blum's kidney.

Urine began to pool in Blum's abdomen, an issue his Intervention Radiologist claimed didn't require urgent attention. Two days later, Blum was rushed to the ER with life-threatening sepsis. He began emergency kidney dialysis, and he soon learned the intervention radiologist's errors in judgment had almost cost him his life: he was just twenty minutes from complete organ failure.

His life for the next ten months (and 22 surgeries) revolved around managing his internal health to stay alive. His right kidney was removed, and Blum became kidneyless.

While Blum pursued dialysis at a dialysis center, the second devastating medical error struck.

His nephrologist's insistence on achieving a highly unrealistic dry-weight (your weight without extra fluid in your body) left Blum with acute hypotension. His blood pressure hovered around 70/40 "on a good day," explained Blum, and he fainted every time he tried to stand. "I lost 80% of my visual field due to his negligence," said Blum. Today, his vision loss is close to 85%.

The journey was harrowing, and it led Blum to a surprising new purpose.

"When I saw how poorly I and other patients were being treated, I became a patient advocate," he explained. "I fight for our right to determine our own treatment plans and take back control, including managing dialysis from within our own homes." The travel that was so central to Blum's professional pursuits remains part of his life today: "My advocacy takes me to



dialysis facilities all over the country to talk one-on-one with patients and staff to D.C. to discuss kidney disease legislation so desperately needed by this community."

Blum's speaking engagements (and his upcoming autobiography) center on "not giving up the fight," including living well with cancer, kidney disease, and dialysis and "how to advocate for your rights as a patient and as a human being and take back control from the medical community." In early March, he joined over 100 other advocates on Capitol Hill for the 6th Annual National Kidney Foundation (NKF) Patient Summit and met with lawmakers to inspire change and "put a human face on kidney disease." He will do the same in May and September with the American Association of Kidney Patients (AAKP).

"We cannot stop," explained Blum. "We must continue to walk the halls of Congress and fight for living donor protections, Medicare coverage of immunosuppressant drugs after 36 months, increased appropriation funding to increase awareness and early detection of kidney disease, and, most importantly, to reduce the amount of time that it takes to obtain a kidney transplant through funding research programs like KidneyX or simply not letting transplantable kidneys get thrown away."

One aspect of his advocacy work hits especially close to home: garnering support for the exorbitant out-of-pocket costs associated with dialysis and kidney transplantation. Blum is currently fundraising with the nonprofit Help Hope Live at helphopelive.org to offset some of his own medical costs. Billed charges for a kidney transplant can exceed \$414,800, as [Milliman reported](#) in 2017.

One significant cost that insurance refuses to cover: travel to meet with multiple medical centers with the hope of joining more than one transplant waiting list, increasing Blum's chances of getting a transplant as soon as possible. These costs exceed \$700 per trip out-of-pocket.

"Without a transplant, my life expectancy is very short," said Blum. "Fundraising will allow me the opportunity to see my son graduate from high school, get married, and hopefully grow old."

Donations in honor of Jay Adam Blum at helphopelive.org or by phone at 800-642-8399 are tax deductible to the extent allowed by law and all funds raised will be used to offset medical expenses via Help Hope Live's Southeast Transplant Fund.

Help Hope Live is a national nonprofit that specializes in engaging communities in fundraising campaigns for people who need a transplant or are affected by a catastrophic injury or illness. Since 1983, campaigns organized by Help Hope Live have raised over \$135 million to pay patient expenses.

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