



STATE REPRESENTATIVE
CORY MASON

WISCONSIN STATE ASSEMBLY
66TH ASSEMBLY DISTRICT
REPRESENTING THE RACINE COMMUNITY

To: Members, Senate Committee on Workforce Development, Public Works, and Military Affairs
From: Representative Cory Mason
Date: January 28, 2016
Re: Senate Bill 517, Relating to: leave from employment for the purpose of serving as a bone marrow or organ donor and providing a penalty

Chairman Roth and members of the Committee, thank you for holding today's hearing on Senate Bill 517. I am pleased to coauthor this critical, bipartisan legislation with Senator Alberta Darling (R-River Hills) and Sen. Bewley (D-Mason). Senate Bill 517 has broad support from members of Wisconsin's medical and bone marrow and organ donor communities, as well as from families who have had their lives saved by organ donation, and will ensure Wisconsinites who wish to donate organs get the time off work necessary to make a donation. Organ donors will now be able to take six weeks of unpaid leave to recover from organ donation surgery

I was inspired to coauthor this legislation by a constituent whose life was saved by an organ donation. She urged me to look for new solutions to assist the over 2,000 Wisconsinites waiting for an organ donation. When researching this issue, I discovered many middle class Wisconsinites want to become organ donors, but are unable to get the leave from work necessary to donate and recover. Senate Bill 517 ensures that a broad range of individuals looking to donate organs or bone marrow are able to give the gift of life to individuals who may not be directly related to them.

Senate Bill 517 will also assure potential bone marrow and organ donors that they will have the time to recover from an operation and return to work, without worrying about losing their job security. This should increase the number of bone marrow and organ donors in our state, and reduce wait times for Wisconsinites who urgently need a donation from a living organ donor.

I am pleased that a broad, bipartisan group of legislators is cosponsoring Senate Bill 517. It is my hope that this legislation will move through the Legislature quickly and be adopted soon.



January 28, 2016

Good afternoon Chairman Roth and committee members. Thank you for allowing me this opportunity to share testimony today. My name is Juliet Kersten and I am a Vice President for Children's Hospital of Wisconsin.

Children's Hospital of Wisconsin serves children from every county in the state. We have inpatient hospitals in Milwaukee and the Fox Valley. We care for every part of a child's health, from critical care at one of our hospitals to routine checkups in our primary care clinics. Children's also provides specialty care, urgent care, dental care, emergency care, school health nurses, Foster care and adoption services, family resource centers, child health advocacy, health education, pediatric medical research and the statewide poison hotline.

I am speaking today on behalf of Children's in support of Senate Bill 517, which would allow an employee to take up to six weeks of leave for the purpose of serving as a bone marrow or organ donor. I would like to recognize the authors of this bill, Senator Darling and Representative Mason, for their work on this issue. There has been a great collaboration of supporters from across the state that has allowed this important legislation to move forward. Children's was proud to host a press conference earlier this week with partners throughout Wisconsin to show support of this bill.

Being a donor improves the lives of others through transplantation, therapy, research, and education. While there have been amazing advances in surgical transplants allowing us to save the lives of children and adults that were not imaginable a few years ago, on average, 22 people die each day awaiting a transplant. One organ donor can save the lives of up to eight people. This bill will go a long way in helping to save and enhance the lives of people awaiting transplant.

One of our patient families joined us at the press conference to tell their story. They could not be here today but have given permission for me to share a little bit of their story. Linda Bevec and her daughter, Claire, from Kenosha are aware of the pain and difficulty that families going through organ transplant face. Claire was born with a rare kidney and liver disease, causing her organs to fail at only eight years old. Because no one in the family was a match, the Bevec's had to look for unrelated donors. Luckily, Claire found a generous family friend to donate his own kidney. Claire's kidney transplant took place at Children's Hospital in 2010. Claire is now a freshman in high school and enjoys being in school plays and musicals, horseback riding, playing the piano, singing, following her favorite Broadway stars and hanging out with her older brother Frank and younger sister Grace.

Claire's donor Jeff shared the following comment about this legislation:
"If it wasn't for my accumulated personal time off and vacation time that I used, I probably would not have been able to donate my kidney to Claire. I think this is a wonderful idea and

would allow the individuals who don't have a lot of vacation or sick/personal time banked to follow through with being a donor and saving a life."

More than 123,000 people are on the waiting list for organ donation. In Wisconsin alone there are over 2,300 people awaiting transplantation. Organ transplantation has a greater rate of success when there is a living donor. Living donors are rare; it is not often someone is willing to forgo their own organs to donate to a family member or friend. Time off of work for the surgery and recovery time, plus the financial risk and jeopardizing their job security, are huge barriers for live donors.

This bill would make living donation a viable option for many more people. Removing barriers to organ donation is one of the greatest things we can do as a state for our children and adults awaiting transplantation. This legislation will save lives.

Thank you Chairman Roth and committee members for allowing me to submit testimony today in support of SB 517. If you have any questions you can contact me at JKersten@chw.org or via phone at 414-907-3928.

January 28, 2016

Dear Mr. or Madam Chair and members of the Senate Committee,

I am Linda Bevec from Kenosha and I'm submitting my written testimony to you in support of Senator Darling's bill for **Bone Marrow and Organ Donation Employment Leave** because I am not able to be there in person today due to my mother having emergency surgery yesterday afternoon.

I am the mother of a beautiful 14 year old daughter, Claire Bevec, who was born with a rare kidney and liver disease called ARPKD/CHF. This disease is progressive from birth and most often requires a kidney and liver transplant in the early years of life. Claire survived the critical first year which nearly 40% of babies born with ARPKD/CHF do not survive, and after 9 years of chronic illness and treatments to keep her as healthy as possible, she was in kidney failure and in need of a transplant to save her life.

No one in our immediate family had the same blood type as Claire so we immediately sought a living donor for her because the donation can be done faster than waiting on the donor registry and the outcome is healthier long-term. A very generous family friend, Jeff Albrecht, offered to be her donor and was found to be the best match for Claire. On December 31, 2010 Jeff not only gave our daughter the precious gift of his own kidney, but a future we weren't sure she'd ever have.

Today Claire is a freshman at Saint Joseph Catholic Academy in Kenosha where she enjoys being in school plays and musicals, riding horses, playing the piano, singing and spending time with her family and friends. She hopes to study theater or medicine in college and make a difference by helping and inspiring others with the gift of life she's been given.

Claire's donor, Jeff, is a husband and father of three girls and when he decided to give Claire one of his kidneys 5 years ago he was not only doing something incredibly selfless, loving, and generous, but he was putting his own life at risk to save hers. And, as the main provider for his family, he needed an employer who understood the value of saving a life and who would allow him the full 6 weeks off work for a healthy recovery after surgery. Jeff was very fortunate he had that kind of employer and he banked all his own vacation and personal days so he could take 6 weeks off for recovery and return to his same position in management without repercussion. But, had Jeff **not had** an employer who allowed him the 6 weeks off work to save our daughter's life, **he would not have been able to do so.**

Senator Darling's proposed bill will save countless lives in Wisconsin. Lives that matter and are worth saving. Lives that are certainly worth allowing a willing and caring organ or bone marrow donor the needed time off work for a healthy recovery after saving a life. Individuals like Jeff are true heroes; they are altruistic to the core and fully embrace the suffering of others by sacrificing, literally, part of themselves to save a life not even related to them. It is a shame to

turn countless potential donors away because they are not allowed the time off work for recovery in exchange for **saving a life**.

This bill would will also increase the pool of viable living donors for faster matching, healthier transplants, and possibly even lessen the long wait time for those individuals on the UNOS list who have no living donor options.

I wish you could meet my daughter Claire today and see for yourself what a life saved by living organ donation looks like. She hopes to grow up in a state that truly values life and all the heroes like Jeff who make unrelated organ donation possible for the thousands of children and adults in this state waiting and hoping to receive the gift of life she's received.

There are so many more individuals out there like Jeff willing and able to donate and save countless lives in Wisconsin if only they had the support of this bill to guarantee them time off work to be the heroes they are called to be.

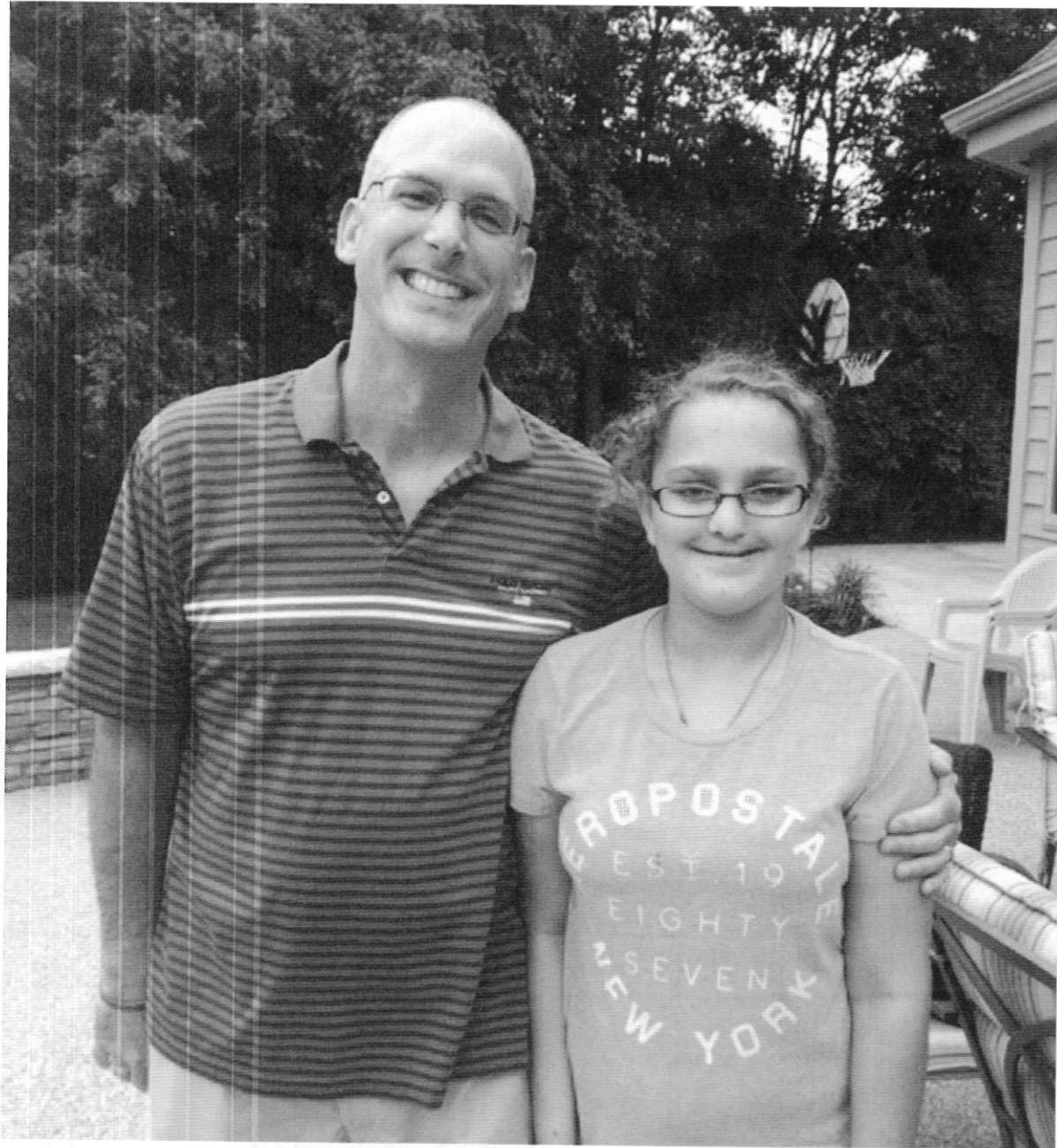
Respectfully yours,

Linda & Claire Bevec

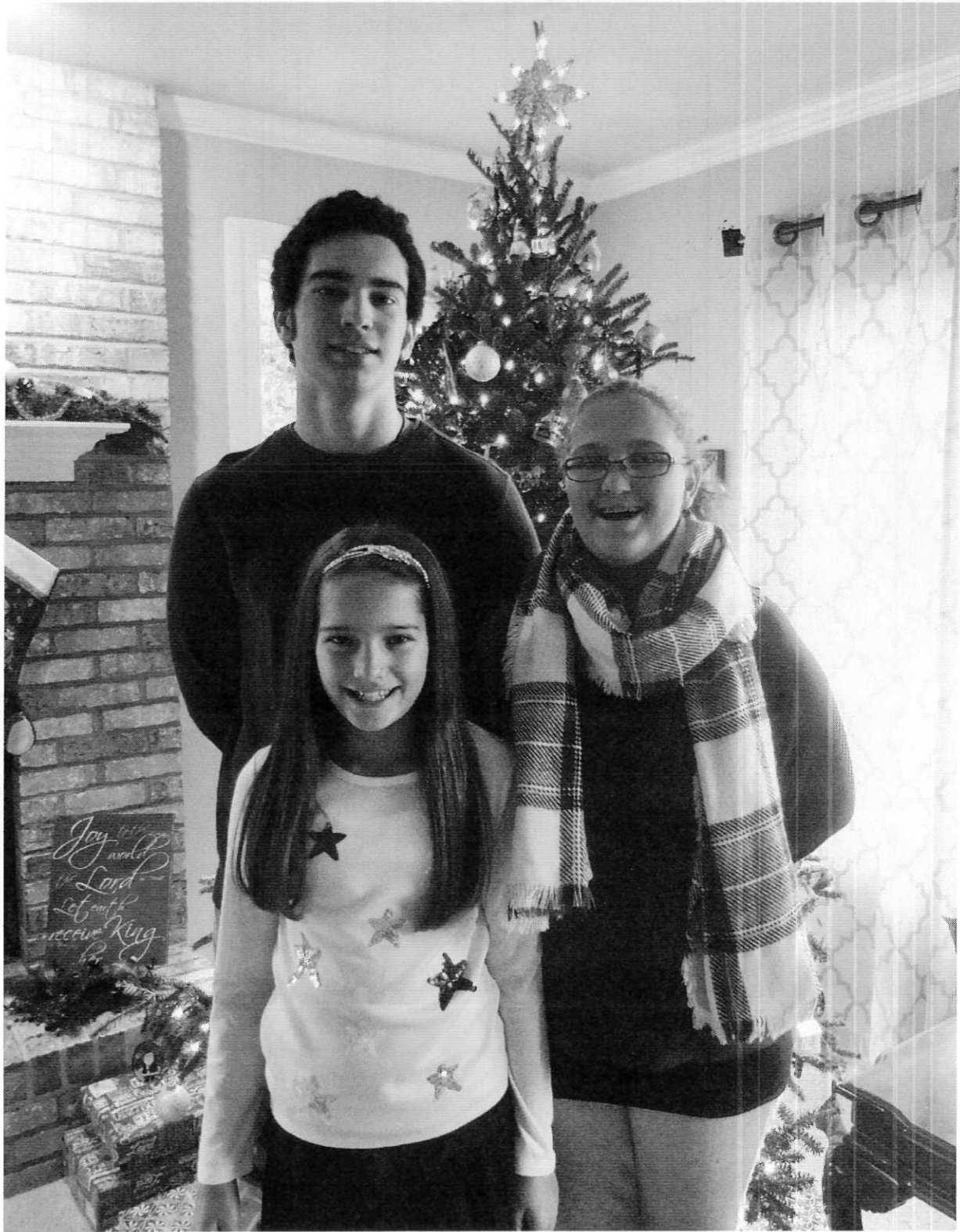
1731 34 Avenue

Kenosha, WI 53144

Linda.Bevec@gmail.com



Claire Bevec's kidney donor Jeff Albrecht with Claire



Frank, Claire (on the right) and Grace Bevec