

## **Personal Story of FA patient Keith Andrus's Autopsy & Tissue Donation**

By Raychel Furr Bartek (Keith's mom)

None of us likes talking about death, but at some point, it happens to each of us.

Patients with FA and their families have expressed interest in donating tissues and organs for FA research after death. They understand this donation will advance research, leading to a treatment or cure.

I'm sharing my son Keith's story about his donation to the FA Autopsy and Tissue Donation Program with the hope that you will personally know the details of our family experience and consider participation in this program.

Keith passed away due to heart failure associated with FA at the age of 24. His cardiologists kept his heart successfully working for 12 years with heart failure medications. However, his heart function severely declined when he was 23 years old. At that point, only one medication, a vasodilator, was available to keep his heart weakly functioning. It was administered through a PICC line 24/7. Eventually, he reached the maximum effective dosing and there were no other options to prolong his life. For this reason, his cardiologist let us know that his time was limited. For Keith, the infusion of the vasodilator kept him alive for four more months. He died less than 24 hours after the PICC line was removed.

Prior to his death, Keith made it very clear that he wanted his tissues and organs donated for FA research. He hoped he could make a difference with his donation and that one day no one else would have to live or die with FA. He also requested that any tissues or organs not needed for FA research be recovered per his Organ Donor Registry designation.

We contacted FARA and Dr. Arnulf Koeppen to learn next steps.

Dr. Koeppen, a neurologist and neuropathologist, is at the VA Medical Center in Albany, NY, and is the principal investigator for the FA Autopsy and Tissue Donation Program.

We learned that, following Keith's death, there would be a very short window of time in which the recovery could take place. Usually 36 hours following death is the max window for tissue recovery, but the preference is for 24 hours.

We received a consent form from Dr. Koeppen for our signature to approve the tissue recovery per the protocol he provided to the clinical recovery team. We provided the name of the funeral home that would handle Keith's arrangements and the place/jurisdiction where Keith would pass away – our home in Fairfax Co, VA. Otherwise, we would have provided the location of the hospital or care facility at which

Keith would pass.

Keith died on a Friday evening and we notified FARA and Dr. Koeppen. The wheels were put in motion behind the scenes to assure a timely recovery procedure according to the research protocol-- Dr. Koeppen, the local coroner, the funeral home, the tissue recovery team, the hospital, and FARA were hard at work. The local coroner arrived to certify death, followed by the funeral home's vehicle arriving to take Keith to the hospital where the tissue recovery was to take place. As a mom, it was the saddest time in my life EVER. I was so glad that a process was in place to coordinate Keith's autopsy and tissue donation.

On Sunday morning, we had an appointment with the funeral home to finalize arrangements for Keith's final wishes of direct cremation after the tissue and organ donation. We were able to view Keith one last time. I was a bit apprehensive about what he would look like since I knew the tissue and organ recovery procedure had taken place. To my relief, he looked like my handsome and beautiful son. He looked at peace after a hard-fought battle with FA.

Ironically, Keith told me in his final months that he wished he could've traveled more. As it turned out, he did! Dr. Koeppen informed me that the FA Autopsy and Tissue Donation Program has sent samples all over the USA and Europe—and most importantly, research findings from Dr. Koeppen's lab, as well as from US and international researchers, have been published using Keith's donation and that of other FA patients. Even though our Keith is gone, his contributions are still providing answers in FA research.

Having gone through this process with my son, I made the decision to be the FARA Liaison to this important program and help other families with the process.

If you would like more information on enrollment or if you have any other questions regarding pre-planning or post-mortem donations, please email: [tissuedonation@curefa.org](mailto:tissuedonation@curefa.org). If your loved one with FA has passed, please note that participation in the program MUST take place within 24-36 hours of death.

If you wish to speak with someone who has gone through this with their loved one, please feel free to email: [pridesmill@yahoo.com](mailto:pridesmill@yahoo.com) or call me: 605-430-5375.

-Raychel Furr Bartek