



HAND LETTERING BY ASHLEY WILLERTON

By Christina Frank

For members of the PKD community, tattoos can have very special meaning.

For years, people have been using tattoos to express their political and social beliefs or to raise awareness of causes they are passionate about. And that's certainly true for these members of the PKD community. The ink they proudly wear represents not just their own struggles but also those of the loved ones they have lost to PKD, and the family members who are threatened by it.

"They are part of my history, just like scars."

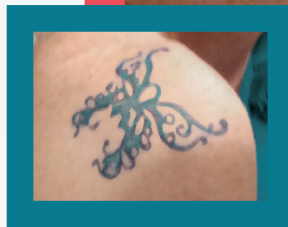


**Susan Dauer, 43,
St. Clair, Minnesota**

My tattoos are representative of two

chronically painful diseases I have that currently have no cure. I got the first [tattoo] in 2013 in remembrance of the two kidney surgeries I had. The second one, on the left shoulder, was done in 2018 in remembrance of battling PKD and PLD [polycystic liver disease] for five years.

Some people wonder what I am going to think about my tattoos when I turn 80. I usually tell them I think I will be more worried about if I can feed myself or make it to the restroom. They are part of my history, just like any scars. I'm not a crafty, artsy person, but they are my way of expressing myself.



Think Before You Ink

Tattoos can be a great way to express yourself and raise awareness, but they're not without risks. Here's how to get a tattoo safely and avoid an infection:

- ① Make sure that the tattoo parlor is reputable and fully licensed (not all states regulate tattoo parlors) and that your tattooist is highly experienced.
- ② Check that work surfaces are clean and that the tattoo artist is wearing sterile disposable gloves and using single-use needles and tubes.
- ③ Ask where the ink was manufactured. Nonmetallic organic pigments made by large, established manufacturers are ideal.
- ④ Consult a doctor immediately if you see any signs of infection, such as redness, swelling, or pus.



“Hope for thousands of others who suffer with this disease.”



**Naomi Best, 55,
Port Lincoln,
South Australia**

I was formally diagnosed in 2000, after my cousin [told] me of our family history of PKD. The disease came from my father's side of the family. His mother died in her mid-40s from it. My father passed away when I was only 5, and my mother never kept in contact with his side of the family, so my brother and I were never tested. I am now at stage 4.

I have had three children, one who passed away as a baby. Both my son and daughter have now been

diagnosed. I have always had an interest in tattoos and have quite a few already. All of my tattoos have meaning, including tribute tattoos for my son, brother, father, and husband, who have all passed away.

My local tattooist, Dave, came up with this design and added flowers to tie it in with the other tattoos that I already had on my right arm. He chose a flowing script and had the teal ribbon replace the “o” in hope. Hope for a cure, hope for transplant, and hope for the thousands of others who suffer with this disease.



“It’s a great conversation starter.”



**Michelle Ensmann,
29, Point Pleasant,
New Jersey**

I got my tattoo

shortly after I was diagnosed at 18. After being upset about my diagnosis for a few days, I’ve had a positive outlook ever since. I’ve had my dad as a great role model. He has had his transplant for over 25 years and sets a great example to enjoy every moment and not take life for granted.

I actually drew it myself. I got the sunflower for my mom and the ribbon for me and my dad. My mom loves sunflowers and my dad has PKD, so the stem of the sunflower goes into the ribbon for PKD. Underneath, it says “strength,” which I got to remind myself [of] the strength and courage both of my parents have had in dealing with this disease, and that I would have to have, too.

People comment on my tattoo when it’s seen in the warmer weather. I often hear that it’s beautiful or people ask what it says. It’s a great conversation starter, and I didn’t realize it when I got it, but it’s a great way to raise awareness about PKD!



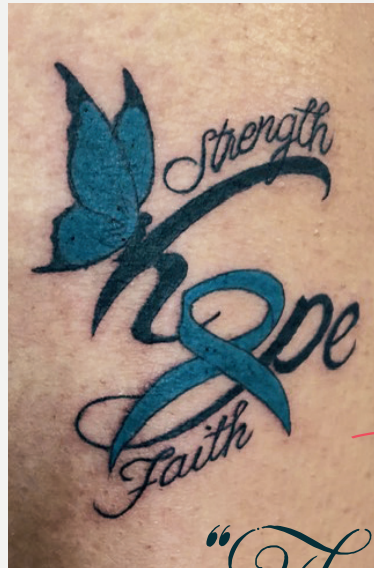
Dawn Rice, 43, Shirley, New York

Growing up in a household where PKD was an everyday topic and seeing many loved ones fight this disease, I knew one day I would get a tattoo for PKD. I thankfully do not have PKD, but my dad, brother, uncle, and cousins all do. I have lost several [relatives] to this disease.

"The ones we love never truly leave us."

When my dad started dialysis 19 years ago, my twin sister and I spoke about getting one together, but life got in the way. We decided for our 40th, we would do it.

It was hard finding something that was different from what other people had and that had a special meaning to me. They say that the ones we love never truly leave us and that every time you see a cardinal, it's a loved one who passed visiting you. I checked multiple Google images and came across a feather in black with the ribbon half in pink, and I thought, "Wow, a cardinal feather in red representing loved ones and the PKD ribbon in teal would be different."



"The butterfly represents life."



Linda Roney, 72, New Port Richey, Florida

I do not have PKD myself, but my husband of 43 years passed [from PKD] in 2010. My son Michael, who was 21 at the time, wanted to donate a kidney to his dad. When he was tested, he found out that he also had PKD. I have two sons who both have PKD and two grandchildren of six so far, with the possibility of more being diagnosed. My heart just breaks for them.

Not being a tattoo person, especially at my age, I had thought about doing this for some time to honor my family members who have PKD. The words are self-explanatory: hope for a cure, strength to overcome, and faith to help them through this terrible ordeal. The butterfly represents life. •