



CONNECTING WITH OTHERS

Through the PKD Connect Center

By Zseraldina Ferenczi

My name is Zseraldina Ferenczi, and I am the Community Outreach Coordinator at the Polycystic Kidney Disease (PKD) Foundation. I also have the privilege to support the PKD community through our new PKD Connect Center, launched in July 2018. Our PKD Connect team is dedicated to providing patients and families with resources, emotional support and an opportunity to get connected with people who have similar experiences. With PKD Connect, no one faces PKD alone. PKD Connect staff understand that patients, family members or friends impacted by PKD sometimes need advice, encouragement or a shoulder to lean on from someone who knows firsthand what you're going through. We offer a variety of services, so no one will ever have to face PKD alone.

One such service is the PKD Connect Mentoring Program. This peer-mentoring program delivers excellent patient-centered support intended to help people manage their conditions by connecting them with mentors from similar life circumstances or with similar health conditions. Whether you or your loved one has just been diagnosed or

is getting ready for dialysis or a kidney transplant, PKD Connect mentors are here to listen to concerns and share their own experiences and perspectives. PKD peer mentors are carefully selected and trained experts who can provide support, guidance, education and ideas for improving and managing their mentees' overall health. PKD Connect mentors are a valuable part of the PKD Connect Team who can empower their mentees to move forward with their lives after being diagnosed with PKD. Mentors also encourage mentees to control and manage their health in a way that will allow them to live a longer and happier life. Risa Simon, one of PKD Connect's outstanding mentors, has had a long battle with PKD. In 2010, she secured her own preemptive living donor transplant, and now she dedicates her life to inspiring others. This is what she wrote: *"My purpose is to give back what my mentor gave to me. I hope to help PKD patients believe in themselves and the possibility of a better tomorrow. I'm here to encourage them to become their own best advocate, bypass dialysis, and execute strategies to find potential donors."*

Our HOPE line offers callers general information about PKD and access to resources to help address concerns. The 800-PKD-HOPE (753-4673) number is

What is PKD?

According to the PKD Foundation, "polycystic kidney disease (PKD) is a genetic disease (passed from an affected parent to their child) causing uncontrolled growth of cysts in the kidney eventually leading to kidney failure. It affects all racial and ethnic groups equally". A geneticist, which is a physician with special training in genetics, can help evaluate, diagnose, and manage PKD. Genetic counseling will be helpful to understand the role of genetics in PKD.

a patient support phone line that anyone affected by PKD can call. Whether people are looking for emotional support, resources, or are seeking help with long-term survivorship, PKD Connect staff is available to help.* The PKD HOPE line is available between 8:00 a.m. and 5:00 p.m. Central time, Monday through Friday.

Through PKD Connect, I hope everyone impacted by PKD will find support and encouragement to fight PKD and live life knowing that you are not alone.

**The PKD Connect is an information and referral line and is not staffed by clinical professionals. It does not provide medical services, diagnosis, treatment recommendations or laboratory test analysis. Its staff can only provide information based upon published materials that have been approved by the PKD Foundation's Scientific Advisory Committee.*