Patient and Caregiver Support

Where Can I Find Help for ADPKD?

There are many organizations and resources in the PKD community available to help you and your loved one with ADPKD. To learn more and connect with others going through similar experiences, visit the sites below.

Foundations and informative sites*

ADPKD-focused

Improving Awareness & Patient Outcomes

PKD Foundation | pkdcure.org

Dedicated to PKD research and education

PKD International | pkdinternational.org

• Global alliance of patient organizations worldwide, dedicated to finding a cure and offering disease education for PKD

Renal-focused or general health

American Association of Kidney Patients (AAKP) | aakp.org

• Education and advocacy for kidney patients in the United States

American Kidney Fund | kidneyfund.org

• Provides charitable assistance to dialysis patients who need help with the costs of treating kidney failure

MedlinePlus | medlineplus.gov

• A service of the U.S. National Library of Medicine, with information on over 900 diseases

National Kidney Foundation | kidney.org

· Peer support and information for kidney patients

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Online communities*

AAKP Renal Support Groups | aakp.org/support-groups

• A list of renal support groups, broken down by state

PKD Health Notes | pkdcure.org/blog/category/pkd-health-notes

• Health and nutrition blog for PKD patients written by a renal dietitian

PKD Will Not Beat Me | pkdcure.org/blog/pkd-will-not-beat-me

A PKD support blog written by a PKD patient

Caregiver Support*

Administration on Aging (AoA) | acl.gov/about-acl/administration-aging

 An agency in the U.S. Administration for Community Living, provides leadership and expertise on programs, advocacy, and initiatives affecting older adults and their caregivers and families

Family Caregiver Alliance | caregiver.org

• Dedicated to improving the quality of life for caregivers and those they care for through information, services, and advocacy

*Not an exhaustive list.

Questions? Concerns? Never hesitate to ask.

You have a right to know everything about your health and your care.