



PCDF Registry

The PCD Foundation Registry (PCDFR) collects important health and demographic information about individuals with primary ciliary dyskinesia (PCD). Participating PCDF Clinical & Research Network Centers (CRCN) enter data on individuals who agree to participate in the PCDFR.

This information is used to assist healthcare teams to provide care to individuals with PCD, drive quality improvement initiatives at care centers, and create PCD care guidelines. Researchers may also use information from the PCDFR to study PCD treatments and outcomes and to design PCD clinical trials.

Join the Registry

Interested in enrolling in the PCDF Registry?

The PCDF Registry is open to PCD patients who are followed at a PCDF accredited site and who meet eligibility criteria. The registry is actively expanding, with additional sites regularly onboarding. Ask your PCD physician about participating.

To learn more about the PCD Foundation and the PCDF Registry, contact info@pcdfoundation.org or visit www.pcdfoundation.org.



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