PCD
FOUNDATION™
PRIMARY CILIARY DYSKINESIA

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 participating in the PCDF Registry?

The registry is actively expanding, with additional sites regularly onboarding.

You must be an accredited PCDF Center to participate in the PCDFR. To learn more about next steps and additional requirements, please contact the PCD Foundation at info@pcdfoundation.org.

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www.pcdfoundation.org