How the PC Project is Driving Progress for People Living with Pachyonychia Congenita

The PC Project, a patient member organization of CSD, supports people living with pachyonychia congenita, or PC, a rare and painful genetic skin disorder that can make walking difficult and, in some cases, impossible. Through patient support programs, research initiatives and data collection, the organization works to improve the lives of those affected by PC.

To raise awareness and highlight its progress, the PC Project recently released its 2026 Impact Report, which showcases the stories, milestones and achievements that shaped its work over the past year. Highlights include:

- More than 3,000 patients connected to the PC Project's global community
- 28 research grants and awards totaling more than $2.3 million
- Patient experiences and information gathered through the PC Project's patient registry

The PC Project also works to advance research. To create additional impact within the skin disease community, it provides genetic testing at no cost to patients, access to expert consultation and individualized support. Central to these efforts is the International PC Research Registry, which provides critical insights into the patient experience and helps inform research priorities and future therapeutic development.

As a valued member of the CSD community, the PC Project continues to demonstrate the impact that patient-led organizations can have in advancing research, fostering connections and improving quality of life for those living with rare skin diseases. The 2026 Impact Report reflects a year of meaningful progress and underscores its ongoing commitment to ensuring that no one affected by PC faces the journey alone.