



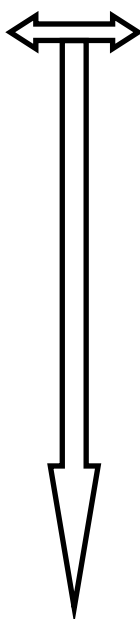
Pachyonychia Congenita Project

Fighting for a cure. Connecting & helping patients. Empowering research.

IPCC Strategic Planning Meeting — May 16, 2018

Patient Community

- IPCRR (Registry)
- PC NewsBrief
- Genetic Testing
- Patient Support Meetings
- Patient Web Meetings
- Patient Advocates
- Physician Consultations
- Meeting



Scientific Community

- IPCC (Consortium)
- IPCC Newsletter
- IPCC Meetings
- Publications
- Industry Partnerships
- Translational Research
- Grants
- Educational Outreach

More Awareness of PC • Treatment Options

Clinical Trials

IPCC Attendees

Pierre Coulombe
David Hansen
Roger Kaspar
Wes Kaupinen
Birgit Lane
Edel O'Toole
Dennis Roop
Eli Sprecher, IPCC Chair

PC Project Attendees

Jack Padovano
David Schwartz
Janice Schwartz
Mary Schwartz
Frances Smith

PC Project is a Public Charity in the US & UK

The Board Of Trustees has fiscal responsibility to use resources to provide patient support and develop treatments for those with PC.

Priority	Topics – listed alphabetically and not by priority	Comments	Who can lead this goal?
	Clinical Studies/Trials	Identify current and future studies	
	Funding Opportunities for PC Project		
	Grants by PC Project		
	IPCC Newsletter		Edel O’Toole, Editor
	IPCC Meeting 2019	Virtual? Pre-SID?	
	IPCRR Research Registry	Changes? Opportunities?	Dave Hansen
	Partnerships with Industry		
	PC Animal Model	Mouse? Other?	
	PC Funded Research Goals	Clinical vs pre-clinical; Devices vs Drugs)	
	PC Grand Rounds/Educational Outreach	Can we increase awareness through this effort?	
	PC Physician Network	Can we build a group of physicians who treat PC	
	Publications (current & future)	Identify key topics and authors for future publications	
	Research Focus	Diversification vs Unification	
	Virtual Lab Meetings		



YOUR THOUGHTS, SUGGESTIONS, CONCERNS, PRIORITIES

Please return to a PC Project attendee.

These will guide the PC Project Board of Trustees as they lead PC Project forward.
We value your input and want to ensure your ideas are not lost but acted upon.

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