

PATIENT SYMPOSIUM

4 September 2024, 12:30-15:00



Confirmed Speakers



Mandy Aldwin-Easton (UK)



Tim Baker (UK)



Tom Baker (UK)



Ncoza Dlova (SA)



Antoine Gliksohn (FR)



Antoni Gostynski (NL)



Fernando Larcher (ESP)



Edel O'Toole (UK)



Neil Rajan (UK)



Janice Schwarz (USA)



Eli Sprecher (ISR)



Núria Tarrats (ESP)



Karin Veldman (NL)

53rd ANNUAL ESDR MEETING
4-7 September 2024, Lisbon, Portugal

PROGRAM



Time		Presentation	Speakers/Moderators
12:30	12:40	Welcome and introduction	Eli Sprecher (ISR), Neil Rajan (UK)
12:40	12:44	Two vital programs of Pachyonychia Congenita Project	Janice Schwarz (USA), Pachyonychia Congenita Project
12:44	12:53	Involvement in the International Pachyonychia Congenita Research Registry and the impact of living with pachyonychia congenita	Tom & Tim Baker (UK), Pachyonychia Congenita Project
12:53	13:07	Involvement in the International Pachyonychia Congenita Consortium and advances in PC research	Edel O'Toole (UK), Pachyonychia Congenita Project
13:07	13:10	Q & A with closing remarks	Eli Sprecher (ISR)
13:10	13:20	Patient narrative European Ichthyosis Network	Karin Veldman (NL), Mandy Aldwin-Easton (UK), European Network for Ichthyosis
13:20	13:35	Elevating ichthyosis research and care by cooperation	Antoni Gostynski (NL), European Network for Ichthyosis
13:35	13:40	Concluding remarks followed by Q&A	Mandy Aldwin-Easton (UK)
13:40	13:50	Break	
13:50	14:00	The burden of albinism from two different perspectives: Europe and Africa	Ncoza Dlova (SA), Antoine Gliksohn (FR), Global Albinism Alliance
14:00	14:15	Albinism: review of on-going research and research gaps	Ncoza Dlova (SA), Antoine Gliksohn (FR), Global Albinism Alliance
14:15	14:20	Q & A with closing remarks	Ncoza Dlova (SA), Antoine Gliksohn (FR)
14:20	14:35	Research in EB - the current situation	Fernando Larcher (ESP), DEBRA International
14:35	14:50	Spanish EB patients' experience of being involved in research and the advocate's role in supporting PPI in research	Núria Tarrats (ESP), DEBRA International
14:50	15:00	EB Panel discussion & Closing words	Neil Rajan (UK), Fernando Larcher (ESP)