

CLL Advocates Network (CLLAN) and iwCLL Joint Session

Friday, 12 September 2025

Session Topic 1:	Understanding immune related challenges in CLL, research developments, unmet needs and collaboration to improve patient outcomes	
Session Overview:	Exploring approaches and practical solutions to bridge the knowledge and evidence gap. How do we continue to move the needle of change forwards as a multidisciplinary stakeholder community to address unmet needs and improve patients’ QOL and outcomes in relation to SID?	
Time	Presentation Topic	Speaker(s)
15:30 - 15:45	Bridging the evidence and knowledge gap, national directories, and data-driven approaches that capture patient focussed outcomes, extrapolate trial data and real-world data to improve care and practice	Professor Carsten U. Niemann Copenhagen University Hospital Denmark
15:45 - 16:00	Improving patient outcomes as a global multistakeholder community, 2025 CLLAN project launch of The CLL Immune Challenges Taskforce – (CLL IC Taskforce)	Nick York, Patient Advocate CLLAN SC, Leukaemia Care United Kingdom Professor Stephen Opat Monash Health Melbourne, Australia
16:00 - 16:15	Discussion and Q&A	
Session Topic 2:	Patient and Public Involvement and Engagement in research (PPIE), building capacity in patients and research teams	
Session Overview:	Exploring examples of good practice and principles, evidence of benefits and impacts. identifying challenges and solutions to overcome barriers. There is much variation on levels of commitment to an inclusive approach to PPIE around the world. How do we develop capacity to ensure good PPIE and empower patients and research teams to adopt good practices and principles?	
Time	Presentation Topic	Speaker(s)
16:15 - 16:25	PPIE in clinical study development clinical research PI perspective	Professor Anna Schuh Churchill Hospital Oxford University United Kingdom
16:25 - 16:35	PPIE in clinical trial design and performance DKFZ/NCT process, Germany	Johannes Förner, Patient Advocate CLLAN SC Germany
16:35 - 16:45	STaR patient initiative, PPIE patient empowerment and registry, UK	Peter Allen, Patient Advocate CLL Support United Kingdom John Greensmith, Patient Advocate CLL Support United Kingdom
16:45 - 17:00	Discussion and Q&A	