

Dr Nicolas Sireau, Chairman and CEO, AKU Society

Dr Nicolas Sireau is Chairman and CEO of the AKU Society, a medical charity that works to find a cure for and support patients with AKU (also called Black Bone Disease), an ultra rare disease that affects his two sons (www.akusociety.org).

The AKU Society is a fast-growing patient movement, with formal patient groups in the UK, France, Italy, Germany, the Netherlands, Jordan, Belgium, Slovakia, North America and India. It is spearheading an international consortium of biotechs, pharma companies, universities, hospitals and clinical trial centres across Europe, the Middle East, Asia and North America. It works closely with the hospital and university in Liverpool.

Dr Sireau is Co-founder and Chairman of Findacure (www.findacure.org.uk), a new social enterprise that raises awareness into and helps patients with fundamental diseases: extreme and exceptional diseases that advance our understanding of medicine and help us discover potential new treatments (www.findacure.org.uk).

He is a committee member of Rare Disease UK, the national alliance of rare disease groups in the UK, and of the International Rare Disease Research Consortium (IRDiRC). He is also a trustee of DNAdigest, a social enterprise that works on collaborative data cures for genetic diseases.

He is a fellow of the Ashoka fellowship of social entrepreneurs and of the Royal Society of Arts. He is the editor of 'Rare Diseases: Challenges and Opportunities for Social Entrepreneurs' (Greenleaf, 2013) and co-editor of 'The Rare Diseases Patient Group Handbook' (forthcoming). He is co-founder of the Vincent Foundation for brain injury and a former non-executive Director of GenSeq, a bioinformatics company.

Dr Sireau's previous career was in international development, where he was CEO of SolarAid and Sunny Money, two award-winning non-profit social enterprises that he set up. Sunny Money is now the largest distributor of solar lanterns in Africa. He has also written several books on international aid. He has a PhD in Social Psychology.