

John Forman

John Forman is a parent of adult twins who have the rare lysosomal disease alpha-Mannosidosis. His involvement in rare disease advocacy now spans more than 40 years. The first 20 years were very much in a vacuum of knowledge, but his involvement intensified and formalized in the 1990s when genome knowledge and the arrival of the internet transformed the amount of information available, and ease of access to it.

In 1999 John began the establishment of Lysosomal Diseases New Zealand, and assisted with setting up an international group, ISMRD, focused on Glycoprotein storage diseases. In 2000 he formed the NZ Organisation for Rare Disorders and ran NZORD until stepping down in 2015. He continues his involvement as a rare disease advocate with much of his focus on international advocacy issues, and still retains his roles on the boards of LDNZ and ISMRD.

A focus of John's rare disease advocacy is the human rights and ethical dimensions that inform public policy and services. He considers these dimensions are often not sufficiently included in discussions about rare diseases, yet are very important factors that are included in declarations and conventions that most governments have ratified. These dimensions, grounded in moral philosophy, provide an important counterbalance to the pressures of neo-liberal economics when decisions are made in health and disability policy.

John held the Presidency of ICORD from 2014 to 2016 and is still active in the board as the past-President.