

Professor Kevin W Southern

Supporting statement for ECFS Board application

For twenty-five years I have been a member of the Society and for three years have served as an elected member of the Board.

I was elected onto the Board with the expressed aim of improving care for children with CF across Europe, with particular focus on supporting the expansion of newborn screening. After considerable work on designation and the organisation of seven international meetings, we have achieved progress in this area. For me, this has included working closely with colleagues outside of Europe to better harmonise a global approach to diagnostic challenges. It has been an exciting time in the world of CF, but I have no doubt that newborn screening has been one of the key interventions improving the outlook for people with this condition. If elected for a further three years, I will continue to drive forward those activities and build on our progress. I believe newborn screening provides the foundation on which the longer term wellbeing for people with CF is built.

My time on the Board has given me a clearer vision of two themes I feel strongly about and will strive to support if re-elected.

Firstly, I believe that our Society must be focused on patients and their families. This should underpin our direction, drive our progress and determine how we support our members; CF Healthcare Professionals and Scientists. To do this we must continue to work closely with Patient Organisations across Europe and be guided by their agenda. We must maintain a constructive relationship with the pharmaceutical industry but this must be non-conflicted. People with CF should not be discriminated against because of their location or income. This is an enormous challenge, one that is getting more apparent and one the Society should continue to make an absolute priority.

Secondly I will continue to campaign on behalf of Allied Health Professionals, to ensure they are well represented and integral to the Society. To build on this we must work constructively with the bodies that represent these groups and make our future directions consistent.

In 2019 we will host the ECFS Conference in Liverpool and I am committed to ensuring this is a success and has a wide range of activities to support people with CF.

In the world of CF, we have a lot to do and we need to do these things in challenging times. We must reflect on the initiatives that have been successful for the Society, the accumulation of data across the continent through the Registry and the improved access to clinical trials through the Network, and determine how we can ensure these initiatives go from strength to strength and are sustainable for decades.