



Statement: In the position as a ECFS board member

If elected to the Board, I would advocate for optimal care of all people with CF (pwCF) not only in Europe, but also worldwide. As the head of the regional paediatric CF centre of Eastern Switzerland in St. Gallen for more than 20 years, I'm involved in daily care and clinical research, independent of any pharma support or grants. It is very important to me that all pwCF have access and can benefit from the newest CFTR modulator therapy at a reasonable price, and pwCF with rare mutations should benefit from new investigative techniques such as rectal organoids.

As a previous secretary and chair of the CF group of the European Respiratory Society (2014-2020), I have already worked for an optimal cooperation with the ECFS in regard of CF teaching activities and research. Today there are more adult pwCF than children, so a good education of adult pulmonologists is important task for the future.

In my function as president of the Swiss Working Group for CF from 2006-2014, I introduced the CF newborn screening (NBS) in Switzerland. As the current chair of the ECFS Neonatal Screening Working Group (NSWG), the optimisation of existing CF NBS programmes and the introduction of them in all European countries is close to my heart, so that all children can benefit from an early therapy. As an undesirable side effect of NBS, we have more and more unclear diagnoses, so-called CFSPID cases. To better follow and characterize these children, and to be able to estimate more accurately in the future who of these children will develop CF or a CFTR related disorder as adults, we need to build up a CFSPID-registry to prevent later diagnostic odysseys.

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