Cystic fibrosis in Turkey

We read with great interest *The Lancet Respiratory Medicine* Commission by Scott Bell, Felix Ratjen, and colleagues,[1] which gives a comprehensive global perspective on cystic fibrosis care. We were pleased to see that the Commission gave a special focus to cystic fibrosis care in Turkey. However, in the space available, the authors were able to provide only brief details of clinical care in the country and we would like to take the opportunity to provide further information.

Care for cystic fibrosis was first implemented at Hacettepe University in 1974 and a clinicopathological evaluation of infants with cystic fibrosis was published by this centre in 1975.[2] Many cystic fibrosis clinics have since been established across Turkey. To our knowledge, the first report on the epidemiology of cystic fibrosis in Turkey was published in 1973, in which the prevalence of the disease was estimated as 0·03% by the use of sweat chloride tests.[3] The Turkish Pediatric Respiratory Diseases and Cystic Fibrosis Society was the first cystic fibrosis society in Turkey, established in 1995 with the aim of increasing awareness of cystic fibrosis and training health personnel in cystic fibrosis care across the country. The registry referred to in the Commission[1] is actually a national registry known as the Cystic Fibrosis Registry of Turkey, which was established in 2007 by the Turkish Pediatric Respiratory Diseases and Cystic Fibrosis Society. The first comprehensive results of this national registry have been published, in which the demographic and laboratory data of 1170 registered patients from 23 centres, collected in 2017, are reported and cystic fibrosis care in Turkey is discussed in detail.[4] A much more detailed analysis, in which these data are analysed as a whole and on a centre-by-centre basis, is provided in the registry's 2017 annual report of cystic fibrosis, published in Turkish; six centres have more than 100 patients with cystic fibrosis. The Cystic Fibrosis Registry of Turkey has contributed to the European Cystic Fibrosis Society's patient registry since 2016.

Recommended standards of care for cystic fibrosis, provided by a multidisciplinary team and including diagnosis and treatment, nutrition, screening of newborn babies, and sweat chloride testing, are followed in Turkey. Drugs for the treatment of cystic fibrosis are available to all patients, funded by the government, with the exception of the new CFTR modulator therapies, because the current costs of these drugs preclude government funding. Therefore, patients in Turkey cannot afford, and so cannot use, these promising new treatments. The oldest patient in Turkey with cystic fibrosis is now 43 years old. However, because of the lack of longitudinal data, we cannot calculate the life expectancy of Turkish patients.

Our priorities for the future include ensuring the sustainability of screening programmes for newborn babies, providing genetic testing for all patients, expanding the use of sweat chloride testing, implementing the widespread use of measures such as nasal potential difference and lung clearance index, improving patients' nutritional status, and improving transition into adult care and the accessibility of lung transplantation.

We declare no competing interests.

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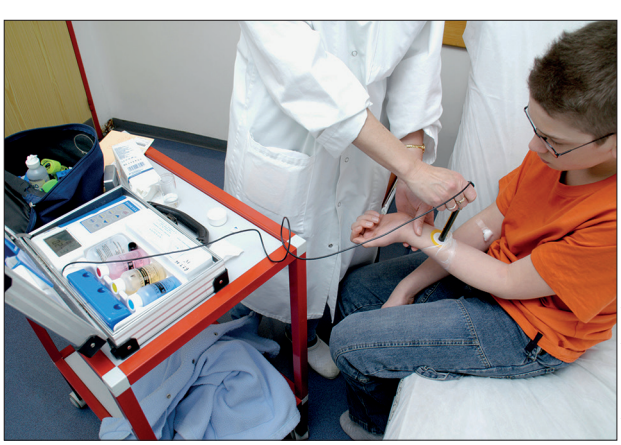
For more on the **Turkish Pediatric Respiratory Diseases and Cystic Fibrosis Society** see http://www.kistikfibrozisturkiye.org



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