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Short Communication

Partnership between cystic fibrosis centres in Europe: The Twinning Project

Pavel Drevinek [a,*], Helen K. Chadwick [b,c], Katarina Stepankova [d], Claire Francis [e], Hilde de Keyser [e], Chris Smith [f,g], Lutz Naehrlich [h], on behalf of the ECFS/CFE Twinning Steering Committee[1]

[a] Department of Medical Microbiology, Second Faculty of Medicine, Charles University and Motol and Homolka University Hospital, Prague, Czech Republic
[b] Leeds Teaching Hospitals NHS Trust, Leeds, United Kingdom
[c] Leeds Institute of Medical Research, University of Leeds, Leeds, United Kingdom
[d] Slovak Cystic Fibrosis Association, Slovakia
[e] Cystic Fibrosis Europe, Belgium
[f] Royal Alexandra Children's Hospital, Brighton, UK
[g] Brighton and Sussex Medical School, Brighton, UK
[h] Department of Pediatrics, Justus-Liebig-University Giessen, Germany

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ABSTRACT

Significant disparities in cystic fibrosis (CF) care persist across Europe. To address these inequalities, the European CF Society (ECFS) has launched the Twinning Project in collaboration with CF Europe. The project promotes structured partnerships between well-established and developing CF centres. Mentor centres from the ECFS Clinical Trials Network (ECFS-CTN) are paired with mentee centres, primarily from Eastern European countries, with the aim of strengthening CF care. Launched in 2020 with eight partnerships, the programme has grown in 2024 to encompass an additional 19 twinning pairs and national patient organisations. Twinning activities include onsite visits, virtual meetings, educational initiatives and translation of learning resources into local languages. Programme evaluation is based on annual progress reports assessing collaboration, training, multidisciplinary team development at the mentee site, and the frequency and mode of communication. Of the 25 twinning pairs that submitted their reports in March 2025, 24 had established regular online communication and 19 had conducted at least one onsite visit. Based on reports received from 23 pairs in March 2026, we identified that the proportion of pairs completing reciprocal onsite visits rose from 24% (6/25) in 2025 to 65% (15/23) in 2026, and the proportion reporting regular clinical case consultations increased from 24% (6/25) to 83% (19/23). One mentee centre was approved as a new ECFS-CTN site. As of 2026, the network comprised 26 mentor centres and 28 mentee sites. The Twinning Project has fostered sustainable collaborations between CF centres and patient communities, contributing to the harmonisation of CF standards across Europe.

1. Rationale for the Twinning Project

The mission of the European Cystic Fibrosis Society (ECFS) is to improve survival and quality of life for people with cystic fibrosis (pwCF). In line with this goal, the ECFS strongly supports professional and educational activities aimed at improving CF care across Europe. In 2014, the ECFS published comprehensive Standards of Care defining best practices and optimal management for pwCF, emphasizing centralized care delivered by experienced multidisciplinary teams (MDT) [1,2]. However, the implementation of these standards was acknowledged to be particularly challenging in under-resourced settings. These concerns were confirmed by a survey conducted in Eastern Europe in 2015–2016 [3], which identified major gaps in CF healthcare provision often associated with insufficient funding, a lack of staff, training, and/or a lack of political prioritisation. Most surveyed countries lacked one or more core MDT members, including CF nurse

* Corresponding author.
E-mail address: pavel.drevinek@lfmotol.cuni.cz (P. Drevinek).

[1] ECFS/CFE Twinning Steering Committee members: Pavel Drevinek, Helen Chadwick, Katarina Stepankova, Claire Francis, Hilde De Keyser, Chris Smith, Lutz Naerlich, Silke van Koningsbruggen-Rietschel, Carlo Castellani, Gary Connett, Jacquelien Noordhoek, Christine Dubois, Andreas Hager, Elise Lammertyn, Mieke Boon, Su Madge, Charles Haworth

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specialists, and 4 of 16 countries did not have a specialist CF centre. Despite these limitations, CF physicians in the region expressed a strong commitment to adhering to the ECFS Standards of Care and highlighted the need for structured support.

To address these disparities, the ECFS launched the Twinning Project in collaboration with CF Europe (CFE), a European umbrella CF patient organisation. Mentor centres are recruited from the ECFS Clinical Trial Network (ECFS-CTN) which comprises high-performing CF centres fully compliant with ECFS Standards of Care, while centres seeking support participate as mentee sites (see Supplementary Table 1 for definitions).

2. 2020: Launch of the project

The call was launched in September 2020, and the ECFS Board approved eight twin partnerships in November 2020 (Table 1). Three of these pairs comprised CF centres that had collaborated previously, while the remaining five pairs were newly matched taking into account factors such as the type of CF centre (paediatric, adult, or mixed) and the availability of a mentor's MDT member who could communicate in the mentee's language. Fourteen applications for mentor positions were declined because far fewer applications were received from prospective mentee sites than from mentor candidates.

Members of the mentor MDT - typically a CF physician, a physiotherapist and a CF nurse - were encouraged to visit the mentee centre within the first six months to identify unmet needs and opportunities for improving CF care. Although the COVID-19 pandemic limited travel, partnerships were successfully initiated in most instances through remote meetings, with in-person visits taking place once restrictions were lifted [4].

3. 2024: Twinning expansion

In 2024, the Twinning program expanded as a joint project of the ECFS and CFE. The primary objectives of this second phase were to recruit additional CF centres and to gain a deeper understanding of CF healthcare needs in mentee countries. To support this aim and empower the CF community as a whole, national patient organisations (POs) were newly engaged, in recognition of their pivotal role in addressing unmet needs (e.g. the lack of adult CF services or trained healthcare professionals), facilitating communication and advocating for optimal care.

A total of 21 mentee centres were paired with 19 mentor CF centres in 'Twinning 2', either through joint mentor-mentee applications or based on the same matching criteria used in the 2020 call (Table 1). As in the first phase, pairs were encouraged to conduct onsite visits, ideally beginning with a visit by the mentor team to the mentee centre. In addition, the project also aimed to facilitate networking between mentor and mentee national POs, as well as between POs and participating CF centres. Well-resourced POs from mentor countries with established advocacy were encouraged to provide guidance and training support to POs from mentee countries.

In close coordination with the ECFS/CFE Twinning Steering Committee, comprehensive support to participating centres was provided by the project team across four main areas (Table 2): (i) regional collaboration and advocacy, facilitated through the South Eastern European

Table 1
CF centres involved in the Twinning Project. Each mentee site is paired with one mentor site which may have 1–2 mentees. The size of a mentee site corresponds to the number of paediatric and/or adult pwCF reported in their application.

Mentee site	Country	Children	Adults	Mentor site	Country	Note
2020 call: Twinning launch						
Varna	Bulgaria	23	19	Southampton (paed)	UK	pre-existing pair
Athens	Greece	0	265			pre-existing pair
Thessaloniki	Greece	0	51	Southampton (adult)	UK	pre-existing pair; twinning closed in 2025 as Thessaloniki joined ECFS-CTN
Skopje (Kozle)	North Macedonia	25	25	Cambridge	UK	pre-existing pair
Bucharest	Romania	60	0	Leuven	Belgium	
Cluj-Napoca	Romania	28	0	Brussels	Belgium	
Lviv	Ukraine	62	0	London (Royal Brompton)	UK	
Odessa	Ukraine	0	15	Jerusalem	Israel	
Zaporizhzhia	Ukraine	0	24			different mentor in 2020–2025
2024 call: Twinning expansion						
Tirana	Albania	118	19	Rome	Italy	
Yerevan (Muratsan)	Armenia	24	9	Munich	Germany	different mentor in 2024–2025; Munich partnered with another mentee in 2024–2025 (discontinued in 2025)
Yerevan (Arabkir)	Armenia	6	0	Zurich	Switzerland	applied as a pair
Sofia	Bulgaria	79	62	Rotterdam	Netherlands	applied as a pair
Nicosia	Cyprus	10	28	Milan	Italy	
Zagreb	Croatia	90	57	Copenhagen	Denmark	applied as a pair
Tallin	Estonia	23	1	Cardiff	UK	applied as a pair
Tartu	Estonia	9	0			
Tbilisi	Georgia	84	10	Hanover	Germany	applied as a pair
Prishtina	Republic of Kosova	102	17	Utrecht	Netherlands	
Riga	Latvia	36	17	Bordeaux	France	
Skopje (Univ Children's Clinic)	North Macedonia	72	34	Berlin	Germany	applied as a pair
Banska Bystrica	Slovakia	0	70	Manchester	UK	applied as a pair
Bratislava	Slovakia	83	1	Barcelona	Spain	
Ankara (Hacettepe; paed)	Turkey	305	0	Leeds (paed)	UK	
Ankara (Hacettepe; adult)	Turkey	0	90	Leeds (adult)	UK	
Istanbul (Cerrahpasa)	Turkey	203	49	London (King's College)	UK	
Ivano-Frankivsk	Ukraine	33	9	Marseille	France	
Kyiv	Ukraine	40	16	Petah Tikva	Israel	
Vinnytsia	Ukraine	23	0	Montpellier	France	

Table 2
Main aims of the twinning expansion programme 2024–2026.

Body	Task
Twinning project team	Establish twinning pairs
	Connect participating mentor and mentee sites
	Provide ECFS learning resources, translation of selected materials into relevant languages
	Facilitate knowledge sharing and networking opportunities between CF centres and POs in different regions
	Organize international events (South Eastern CF Conferences)
	Evaluate individual twinning pairs
Individual twinning pairs	Onsite visit mentor → mentee to identify unmet needs in CF care and formulate feasible goals
	Onsite visit mentee → mentor to learn best practices, to undergo training
	Follow-up visit(s) to address specific needs (subject to approval)
	Regular online communication
	Training of the mentee MDT
	Guidelines and standard operating procedures provided by mentor
	Advocacy

Conferences (SEEC) held in Cluj-Napoca (2024), Pristina (2025) and Tbilisi (2026); (ii) addressing language barriers to education [5] - six subtitled ECFS eLearning modules were translated using AI, verified by local teams and piloted in Ukrainian, Romanian, and Turkish [6]. Subsequently, translations were expanded to include Albanian, Latvian, Estonian, Georgian and Armenian; (iii) financial support for onsite visits, made possible thanks to grant funding from the CF Foundation, the ECFS and CFE budgets. Although travel was limited due to geopolitical constraints, particularly affecting Ukrainian mentee sites, strong partnerships were nevertheless established in such instances [7]; and (iv) systematic evaluation through annual progress reports, which formed the basis for continued support and funding renewal.

4. Assessment and outcomes

The 2025 reports, submitted by 25 of the 27 twinning pairs, were evaluated across four key domains: onsite visits, frequency and mode of subsequent communication, training and educational activities, mentee MDT composition and engagement. Notably, 19 twinning pairs conducted onsite visits (13 single and 6 reciprocal), and 24 pairs established regular (email, text messages and/or online meetings) communication. Six pairs initiated structured clinical case consultations and one mentee site was approved as a new ECFS-CTN site. Only one mentee and one mentor centre did not demonstrate sufficient activity to continue into the next twinning project cycle. The following year, 23 reports were received out of 26 pairs. Fifteen of these pairs achieved reciprocal onsite visits (9 more compared to 2025 reports), and 19 reported regular online meetings dedicated to consulting on patients' clinical cases (13 more than in 2025). For the 2026 evaluation round, we also requested information on changes to the mentees' MDT teams. Importantly, 12 mentee sites reported an expansion of their teams during the twinning period including an increase in staff numbers and/or the addition of new healthcare worker specialties, as well as administrative or research support. Encouragingly, 6 twinning pairs were working on developing adult CF care in mentee sites, 8 mentors attended local scientific events, and 8 mentors provided direct or indirect support to improve local CF care by meeting with Ministry of Health officials or providing letters of support. In summary, the above indicators (i.e., 65% (15/23) of pairs conducted reciprocal onsite visits by 2026, compared to 24% (6/25) by 2025; and 83% (19/23) of pairs were in regular online contact to discuss clinical cases by 2026, compared to 24% (6/25) in 2025) underline the programme's significant progress. Only a small minority of sites were less active, largely due to external geopolitical circumstances, but lower performance could also be affected by barriers such as difficulties arranging travel, communicating in English, taking annual leave or budget limitations.

The reports also provided valuable qualitative feedback on the project (Supplementary Table 2). Substantial engagement was demonstrated by the POs, with those from 8 of 10 mentor countries and 12 of 15 mentee countries participating in the project. Supplementary Figures 1 and 2 summarize the CF sites and POs involved in 2026.

5. Conclusions

The Twinning Project offers a tangible opportunity to establish long-term partnerships between CF centres and communities with the overarching goal of harmonising CF care standards across Europe. Currently, 26 mentor centres are supporting 28 Eastern European CF sites. Thanks to the commitment and collaboration of healthcare professionals in mentor and mentee institutions alike, an increasingly integrated European CF care network is emerging.

Declaration of competing interest

P. Drevinek and C. Smith have received advisory and speaker fees from Vertex Pharmaceuticals. C. Smith has received advisory fees from Nordic Pharma. The other authors have no declarations of interest.

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Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.jcf.2026.06.009.

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