ECFSPR European Cystic Fibrosis Society Patient Registry

Application for the ECFSPR Partnership project (2025-2030) for Cystic fibrosis (CF)-registries from Low- and Middle-income countries outside the WHO European Region

Application for	own centre	for a collaboration of cent	res in your country
Applicant:			
арр	oointed coordinator	for a collaboration of centres in	ı your country
Email address:			
Telephone number:			
Address of CF Cent	re:		
Please attach an ac	Iditional application fo	r each collaborating centre in you	ır country.
Description of CF	care in your centre:		
Number of patients	with CF: Your center	Country estimation _	
Number of children with CF (<18 years old) adults with CF (≥ 18 years old) followed at your centre			
What sweat test dev	vices and measureme	ent is used in your centre?	
No sweat test available GibsonCook (any stimulation,chlorid) Nanoduct			
UTSAT Mad	roduct plus Sweatche	eck or plus Chlorocheck	If other, please specify
Is CFTR-genotyping	ı available in your cen	itre?	
Available in the country Available in the country, but high cost for patients			
Available throug	h transborder coopera	ation Not available in my co	ountry
Not available in r	my country, transbord	er cooperation not possible due to	o legal restrictions
Do you have an inte	ernational medical coo	peration partner?	
No Yes, p	lease share details:		
Do you have experi	ence with or have an e	existing patient registry for CF?	Yes No
If yes, please provid	le details		
The partnership		ne governance rules of the ECFSF	PR and require an ethical approval
patient with Cystic fi	-	ridividual certa c/country and arr ii	normed consent of each participating
The project will s	support the harmonize	d data collection by access to a w	veb-based tool and data management
but I will responsible	e for the data collecting	g and administration in my centre	:/country.
	SIGNAT	URE	
Date	APPLICANT (Printed Name)		
	Send applications to	o: lutz.naehrlich@ecfregistry.eu	<u>ı</u> by 30 June 2025

Lutz Naehrlich

25 May 2025

1