CYSTIC FIBROSIS EUROPE

Organisational Strategy 2018 - 2023

Published October 2018

Introduction

We have designed this strategy in order to define who we are, what we stand for and how we work. This document outlines our priorities and goals for the organisation over the next five years in order to achieve our ambitions.

By 2023, CF Europe aims to:

- Be a powerful and representative voice of people with cystic fibrosis in Europe.
- Champion the best research in line with what people with CF want.
- Fight for better care for everyone with cystic fibrosis across Europe.
- Provide support and best practice for its member organisations.

We want to put people with cystic fibrosis at the heart of everything we do. Our focus must be to understand and act upon the experiences and needs of people with cystic fibrosis and their families at a European level, throughout Europe.

We will achieve a longer and better life for people with cystic fibrosis by working with and supporting the coalition of national patient organisations, collaborating with influential stakeholders, adding value to strategically important initiatives, and building expertise and advocacy capacity for European policy, research and care, we will collectively fight for the advances that matter to people with cystic fibrosis most.

This strategy has been developed alongside member organisations and key stakeholders, during a three-month consultation in 2017.

Background

Since its inception in 2003, CF Europe has established itself at the centre of patient-focused initiatives in Europe, enhancing international collaboration in CF research, and communicating best practice across our community.

The organisation currently supports its member organisations by sharing expertise and contacts through conferences, workshops, its communications and involvement in the development of guidance and standards.

CF Europe supports international collaborations in research by investing in the European Clinical Trials Network (E-CTN) and by facilitating patient involvement in specific research projects, governed by the Patient Organisation Research Group (PORG).

In this period, where disease-modifying therapies are being developed for – but are not yet available to – an ever-widening population of people with cystic fibrosis, and where profound inequalities exist in even basic CF care, we must refocus our mission to ensure that progress is realised for all and that we continue to advance to the day when the disease is finally beaten.

The challenges facing cystic fibrosis across Europe

There are over 42,000 people with cystic fibrosis across 34 European countries and significant challenges face people with cystic fibrosis, their families, healthcare professionals and researchers, which differ significantly from country to country, region to region throughout Europe.

Although 1 of 30 Europeans carry the gene that can cause CF, few people know of the disease and patients and families all around Europe have to fight for understanding, support and access to the appropriate standard of care every day.

CF Europe's ambition is to work in partnership to highlight, challenge, and support member organisations and relevant stakeholders to have a positive impact on these challenges at a European level.

We want to put people with cystic fibrosis at the heart of everything we do. Our focus must be to understand and act upon the experiences and needs of people with cystic fibrosis and their families at a European level, throughout Europe.

Inequity of care

Early diagnosis, regular follow-up by specialists, proper hygiene and correct, timely treatment prolong and save lives and improve the quality of life but we know that this level of care is not available to all.

Across Europe, there are inequalities in outcomes for people with cystic fibrosis, with some children with CF dying before their 10th birthday while others live well into adulthood.

The difference between the number of patients with CF between EU and Non-EU countries is striking, which might be due to reduced availability of specialist drugs, equipment, and trained multidisciplinary staff in non-EU countries.

We cannot accept a gap in healthcare access and the resultant health outcomes meaning that in some parts of Europe, CF is still a childhood disease.

1 of 30 Europeans carry the gene that can cause CF,
few people know of the disease and patients and families all around Europe have to fight for understanding, support and access to the appropriate standard of care every day.

Changing demographics

In some European countries, improvements in cystic fibrosis care have increased survival rates, with median survival increasing in each of the past six decades. This has led to an increased number of adults with CF. Western European forecasts carried out in 2010 indicate that an increase in the overall number of CF patients by 2025, by approximately 50%, corresponds to an increase by 20% and by 75% in children and adults, respectively.

In some Eastern European countries, where provision of the accepted standard of CF care can be limited and uneven both across and within borders, the projections suggest a predominant increase in the CF child population although the CF adult population would also increase .

The increase in the CF population will require a significant shift in how care is delivered and will require the input of a multidisciplinary team, which presents clear challenges alongside opportunities to design sustainable new models of specialist CF care with the patient perspective fully considered. As people with cystic fibrosis live longer, clinical care needs to adapt to adequately care for age-related co-morbidities such as CF-related diabetes and osteoporosis.

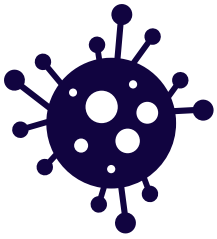
An increasing number of people are living with transplant. When lung function declines and the damage to the lungs is irreversible, transplant is the only viable treatment option. In 2014, over five per cent of people living with CF had received a lung transplant or liver transplant.

Pathogens, antimicrobial resistance, and the risk of infection

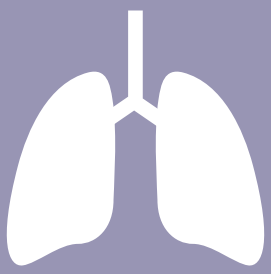
As microbiology tests become more advanced, we are gaining a better understanding of the risks of infection and the transmission of life threatening pathogens like bacteria and fungi.

Inequalities can be seen in care across Europe, in terms of access to microbiology resources and appropriate standards of infection control in clinic.

In children, 12 percent are reportedly chronically infected with Pseudomonas aeruginosa. In Eastern European countries, such as Moldova and Bulgaria, this figure is as high as 65 percent and 50 percent of children, respectively. Even in countries with high standards of vigilance and management of infection risk and treatment, the growing prevalence of antimicrobial resistance creates a significant threat to the current model and tools used to combat this challenge.



Over 42,000 people with cystic fibrosis across 34 European countries and significant challenges face people with cystic fibrosis, their families, healthcare professionals and researchers, which differ significantly from country to country.



An increasing number of people are living with transplant.
In 2014, over five per cent of people living with CF had received a lung transplant or liver transplant.

Access to therapies

Access to even the most basic cystic fibrosis care and therapies can be limited and uneven both across and within borders. In many European countries, especially those with low health budgets, people with cystic fibrosis struggle to get even basic treatments such as certain medicines, medical devices like nebulizers, physiotherapy, nutritional and psychological counselling.

Therapies are becoming available that target the specific CFTR dysfunction of certain mutations. Testing these therapies using traditional Randomised Control Trials (RCTs) is becoming increasingly challenging as their costs increase alongside healthcare payer budget pressures. Bottlenecks emerge within the population of people with CF available and eligible to participate in new RCTs, which makes recruitment challenging and risks delay or abandonment.

Once a therapy is licensed, evidencing its additional benefits to patients within the existing health technology appraisal models is a challenge. However, this challenge is also an opportunity for the CF community to lead the way for other disease areas in designing improved clinical trial models and predictive ex-vivo models, that can generate high-quality evidence that is relevant to regulators and healthcare payers, while decreasing costs and making new technologies more affordable for all.

It is in the context of these challenges that this strategy is designed.

Who we are

CF Europe is striving for a longer and better life for people with cystic fibrosis.

Our vision is a future where a final cure is found and access is given to all persons with cystic fibrosis and a future where all persons with cystic fibrosis have access to optimal care.

Our values underpin the work we do:

We are here to speak for people with cystic fibrosis. Our independence is integral to create the level of impact required to meet the challenges facing CF and to be a valued source of information. The impact we aim to make depends on the objectivity of our work. We have the freedom to speak up and determine our own priorities.

We get our funding from different sources to minimise potential conflict of interest, perceived or otherwise. We are growing the number of companies that we work with through initiatives such as the Round Table of Companies.

We maintain our independence through the following ways:

Accountability

We are governed by a Board who are accountable for our work and for ensuring our independence. The Board is democratically elected by the 39 European member organisations. It agrees our strategy, approves our budget and holds the operational function of CF Europe to account for delivering our work programme.

Our funding

Our funding comes from a diverse range of sources. As a charity, our income is from member organisation, contributions from pharmaceutical companies and biotechnology companies, and EU Grants and other institutions and bodies supporting CF Europe's project work. This income guarantees a consistent stream of funding to support our charitable objectives. Our partnerships are governed by our Policy on Financial Support by Commercial Companies.

Working in partnership

We work in partnership with a range of organisations. We work with groups across Europe including the European Cystic Fibrosis Society, the European Reference Network and Eurordis.

Organisational aims

To meet the challenges for people with cystic fibrosis we will grow as an organisation. In the next year we aim to create capacity within the organisation by appointing new staff members, up-skilling volunteers and providing training and support to our member organisations. **We aim to have the new structure will be in place by the end of 2019.**

This will enable us to achieve our organisational aims, which are to:

Influence

Our work programme will focus on where we can make the greatest impact.

Be representative

Our views will be representative of people with cystic fibrosis.

Involve and inform

We will provide information and analysis for our membership and external stakeholders.

Strategic priorities

Strategic priority 1:
We will represent and defend the interests of people with cystic fibrosis in Europe.

Goals:

- We will influence and lobby to ensure that the views of people with cystic fibrosis are represented in policy discussions at the European Parliament and other governmental organisations.
- To develop a group of trained individuals through the work of the Community Advisory Board to champion the views of people with cystic fibrosis and influence companies, researchers, European level groups, and other external stakeholders.
- We will publish care and research priorities for people with cystic fibrosis in Europe.
- Raise the profile of cystic fibrosis as a health issue on a European level.
- To provide qualitative information to improve healthcare in individual nations.

Strategic priority 2:
We will promote and invest in patient-centred research on a European level.

Goals:

- To engage with European research initiatives, including academic, clinical and basic science research, and industry stakeholders to ensure that the views of people with cystic fibrosis and the wider community are taken into account.
- We will work within Horizon 2020 to raise the profile of cystic fibrosis.
- To support member organisations to promote participation in disease registries.
- To empower member organisations and support members to promote clinical trials to their membership in order to access clinical trials.

Strategic priority 3:
We will influence for better CF care and equal access to medicines on a European level.

Goals:

- We will advocate for the most appropriate model of optimal care for people with CF wherever they live in Europe and share best practice in training and skills for healthcare professionals.
- To advocate for access to all CF medicines and therapies by demonstrating their real world impact on the lives of people with cystic fibrosis through consented data collection and case studies.

Strategic priority 4:
We will support CF Europe's member organisations and strengthen their involvement in the work of CF Europe.

Goals:

- We will keep in regular communication with member organisations.
- We will support best practice in organisational development, advocacy and fundraising.
- We will develop our conferences and events programme to maximise our impact and support our strategic objectives.

Operational plan and review

The Operational Plan will outline how we are going to achieve our strategic priorities. It will outline the resources needed, how we will structure these resources, goals and timescales.

- We will undertake on-going monitoring and evaluation of the Strategic Plan in line with agreed measurable performance indicators and targets for each strategic goal. The evaluation will form a part of CF Europe's work plans.
- The CF Europe Board will be involved in regularly reviewing and appraising evaluation findings with a view to ensuring that evaluation findings and recommendations are acted upon in a prompt manner.
- The Annual General Meeting will hear a report of progress against the strategic priorities and, based on this progress, the meeting will approve future plans.

[i] https://www.ecfs.eu/sites/default/files/general-content-images/working-groups/ecfs-patient-registry/2015_At_A_Glance_Guide_Nov2017.pdf
[ii] Ibid
[iii] Ibid.
[iv] https://www.ncbi.nlm.nih.gov/pubmed/25792639
[v] Ibid.
[vi] https://www.ncbi.nlm.nih.gov/pubmed/25792639
[vii] http://erj.ersjournals.com/content/early/2015/03/18/09031936.00196314.long
[viii] Ibid.
[ix] Ibid, page 7.
[x] Ibid.

Document prepared with assistance from
Chloe Ainsley | Lead Graphic Designer, Cystic Fibrosis Trust

Contact information
For more information about this strategy,
or CF Europe, please contact us: www.cf-europe.eu