Legacy Case
Life-Science

CRISPR Medicine 2026

Accelerating access to treatments for rare diseases

copenhagen legacy lab

For the third time in Copenhagen, the CRISPR Medicine Conference (CRISPRMED26) was held under the theme “Advancing Medicine with Gene Editors”. The hybrid event brought together more than 450 leading scientists, experts, clinicians, and patient advocates, both in person and online, to explore the latest advances and ongoing challenges in CRISPR-based medicine.

Barriers to advancing CRISPR technology

Across Europe, rare diseases represent a significant and growing health challenge, affecting more than 36 million people (PharmaDanmark, 2026). Many rare diseases are caused by single-gene mutations and are severe, life-limiting, and without effective treatment options. Recently, CRISPR technology has emerged as a breakthrough gene-editing tool, creating new opportunities to treat the genetic causes of rare diseases by correcting faulty DNA. Clinical progress is already evident, ranging from the first approved gene-editing therapies to highly personalised, life-saving interventions (CRISPR Medicine News, 2025). However, these scientific advances have not yet translated into equitable patient access across European healthcare systems. Fragmented regulation, legal and economic barriers, limited cross-border coordination, and insufficient sharing of clinical outcomes continue to slow down clinical implementation and weaken collective learning across Europe. As a result, many patients face significant delays, or no access at all, to potentially life-changing therapies, often with severe and irreversible consequences.

CRISPR consortium launched in Europe

To address these challenges, the European Genomic Medicine Consortium (EGMEDC) was convened

CRISPR

CRISPR is a gene-editing technology that enables scientists to precisely modify DNA within living cells. The technology has shown significant potential in treating and, in some cases, curing rare genetic diseases

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"The science is validated. Now we need to accelerate the journey from pre-clinical research to patients. That is why we need a consortium — experts across Europe need to come together"

Jens-Ole Bock
Founder of CRISPR Medicine News (CMN)

by CRISPR Medicine News (CMN) as the first pan-European non-profit initiative dedicated to accelerating access to CRISPR-based therapies. Based in Copenhagen, the consortium brings together 15 founding partners, including leading academic and clinical institutions, industry partners, strategic stakeholders, and non-profit organisations across Europe, with the shared aim of exchanging knowledge, aligning best practices, and addressing key regulatory barriers. Copenhagen Legacy Lab serves as a strategic partner in the consortium and is among its founding members.

The consortium was officially launched during the conference opening reception in Copenhagen. Setting the scene, Stine Bosse, Member of the European Parliament, highlighted legal fragmentation across Europe as a key barrier to patient access to CRISPR-based therapies and called for stronger European coordination. This was followed by a patient perspective from the father of a child living with a rare genetic disease, who shared first-hand experiences of the legal, economic, and clinical barriers families face in accessing treatment. The Chair of Rare Diseases Denmark then emphasised the importance of systematically integrating patient perspectives into efforts to accelerate access to innovation.

Together, these perspectives underscored the urgent need for coordinated European action to accelerate equitable access to CRISPR-based therapies. Against this backdrop, the consortium was formally presented on stage, with all founding partners outlining their shared ambitions and commitments. The launch concluded with a networking reception focused on strengthening cross-sector collaboration and knowledge sharing across Europe.

A Hub for CRISPR Medicine in Europe
Going forward, the EGMEDC Secretariat will be based in Innovation District Copenhagen, positioning Copenhagen as a central European hub for CRISPR innovation. The consortium will meet bi-monthly to exchange insights and track progress and will host its annual meetings in Copenhagen in connection with the CRISPRMED conference. The ambition is to progressively expand participation across Europe by including more countries and institutions, thereby accelerating more equitable and timely patient access to CRISPR-based therapies.

Legacy process

Objective

Strategic alignment
Across Europe, rare diseases affect more than 36 million people, yet access to effective treatments remains limited. While CRISPR-based gene-editing therapies offer transformative potential, their implementation is hindered by fragmented regulation, legal and economic barriers, and limited cross-border coordination. This results in unequal and delayed patient access to treatments across Europe, contributing to serious health consequences.

Ensuring equitable access to CRISPR-based treatment for patients with rare diseases is therefore a strategic priority for both Denmark and CRISPR Medicine News (CMN). Achieving this requires strengthened coordination across clinical, academic, regulatory, and industry stakeholders at the European level.

Objective

- To improve access to CRISPR-based treatments for patients across Europe through the establishment of a European CRISPR Consortium based in Copenhagen.

Stakeholder involvement
CRISPR Medicine News (CMN) established the European Genomic Medicine Consortium (EGMEDC) and hosted its launch, and will continue leading its development and expansion by engaging additional European countries and institutions.

Copenhagen Legacy Lab is a founding member and strategic partner of the consortium and will provide ongoing strategic guidance to strengthen its long-term impact.

Activity

On the opening day of the conference, the European Genomic Medicine Consortium (EGMEDC) was launched to address the urgent need for cross-European collaboration to accelerate access to CRISPR-based treatments.

Legacy process

Evaluation

Outputs (immediately after the activity)
On stage, the 15 founding partners of the consortium, representing 12 different countries, were presented.

Copenhagen Legacy Lab has produced a video from the event highlighting how the European consortium can accelerate access to CRISPR-based treatments. The video is being actively used to mobilise and engage additional members and countries.

Outcomes (after 6 to 12 months)
Since the launch of the consortium, significant progress has been made to strengthen and expand the initiative:

- The consortium has expanded with four new partner members.
- The LinkedIn page has reached 500 followers, representing a 40% increase since the launch.
- A first secretariat hire has been made to establish core functions, including a website, newsletter, and member engagement activities.
- The consortium's executive board has been expanded with two new patient advocate members.

Impact and legacy (after a year)
To be evaluated.

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Copenhagen Legacy Lab is an award-winning strategic initiative under Copenhagen Convention Bureau that drives positive long-term impact from congresses and events.

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