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Belgium

To: Ursula Von Der Leyen, President of the European Commission

Josep Borrell, High Representative of the Union for Foreign Policy and Security
Policy

In copy:

Commissioner for Crisis Management Janez Lenarčič
Commissioner for Equality Helena Dalli

March 2024

Subject: Critical situation for people with cystic fibrosis in Gaza and the West Bank

Dear President, dear High Representative and Vice President Borrell,

I am writing to you on behalf of CF Europe, an organization dedicated to advocating for the right to health for individuals living with cystic fibrosis (CF). We are deeply concerned about the critical situation facing persons with rare diseases in Gaza and the West Bank due to the ongoing war.

Even before the 7th of October, people with CF in Palestine were facing grave challenges in accessing care and treatment. It is estimated that there were at least 300 people with CF in Gaza and the West Bank, with a median life expectancy of 8-15 years. With inadequate inhalation devices, no CF centres, frequent power cuts and restrictions on medication imports, people with CF often had to carry out their physiotherapy and lung clearing exercises in hospitals.

Over the past five months, the situation for people with CF in Palestine continued to deteriorate, and it is now catastrophic. With no official registry and communication blackouts it is difficult to assess with certainty how many patients have since deceased.

Since the escalation of violence on October 7th, CF Europe has kept in contact with our member patient organisations and with CF specialists in Israel and Gaza to get a better understanding of the situation and find concrete ways to help in this humanitarian crisis. After the start of the war in Ukraine, thanks to our member organisations and to collaboration with other rare disease organisations such as Eurordis or Atemspende, we have gained experience responding to the crisis affecting people with CF from Ukraine. We offer this expertise to whoever wishes to support rare disease populations in the admittedly far more complex and politically delicate situation of Palestine.

People with CF and with other chronic diseases in Palestine face a double challenge: while suffering the consequences of violence, they also struggle to receive care for their grave medical condition, affecting the digestive and respiratory tract.

The devastation caused by war has disrupted access to nutrition, sanitation, hygiene and spaces where to exercise, crucial for people with CF. The state of catastrophic food insecurity and imminent famine documented in the [latest IPC report](#) will have unimaginable consequences for all the population.

Beyond being in desperate need of food, water and medication like the rest of the Palestinian population, people with CF and other respiratory conditions, are severely impacted by fumes and dust resulting from bombardments. The risk of catching infections is very high in refugee camps, making those with vulnerable health conditions extremely fragile. There is no access to basic medications such as painkillers or antibiotics, and vital devices, such as inhalers, cannot function without electricity. With hospitals being bombed and those remaining active being overflowed, people with chronic conditions such as CF cannot be admitted. Displaced people with such conditions need specific support from humanitarian groups and authorities, such as the provision of nutrition supplements, specific equipment, vitamins, antibiotics, and this should be factored into any humanitarian response from Europe.

We urge the European Commission and the High Representative of the EU for Foreign Affairs and Security Policy to prioritize the right to health for people with CF, other rare diseases, chronic conditions and disabilities in Palestine.

It is imperative to demand an immediate ceasefire and that action is taken to ensure access to water, food, lifesaving treatments and medical care for those in need. The continuation of hostilities only serves to deepen the humanitarian crisis and further endanger the lives of innocent civilians, including those with rare diseases who are already at heightened risk.

We urge the European Union to use its influence and diplomatic channels to facilitate the delivery of humanitarian aid and medical supplies to Gaza and the West Bank, as well as to support efforts towards a lasting and sustainable resolution to the conflict.

We ask that you do your utmost to explore a humanitarian corridor between Egypt and Palestine to allow vulnerable people with disabilities, rare and/or chronic conditions, including people with CF, to be able to leave and get immediate access to care.

We stand ready to support initiatives or actions aimed at alleviating the suffering of those affected by the conflict. We would be grateful to be put in contact with a designated person or team to discuss this further.

Thank you for your attention to this urgent matter. We eagerly await your prompt response and actions to address this critical health crisis.

Yours sincerely,



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