

Something magical happened last week, or: a letter to the Minister of Public Health

In the Netherlands, Trikafta (known as Kaftrio in the EU) was not available for a long time. It is a revolutionary drug that can in many cases improve the lives of many persons with Cystic Fibrosis dramatically. Many other European countries had already incorporated it into their national health care systems, but not here. The advisory institution told the Minister of Health that, although effective, they thought it was too expensive and the Minister should only allow it for reimbursement unless he could negotiate a hefty price reduction. The negotiations dragged on since last April. I started to get worried about it and decided to write a letter to the Minister. My mother always taught me to only address the highest possible authority in situations like these, so there I went.

The letter turned out rather well. I present it to you here below. I didn't have the e-mail address of the Minister though, and didn't want it to get lost in some lower layer of the departmental hierarchy. So, I contacted the NCFS, the Dutch foundation of Cystic Fibrosis patients and showed them the letter. They liked it and wanted to publish it on their website after some minor fine-tuning. I sent the letter on Tuesday 7th of December 2021. It was processed by the communications department of the NCFS. They planned on publishing it on Thursday 9th. On that day, late in the afternoon, instead of seeing the letter published on the site, I got a glorious phone call from the NCFS with the great news that my letter was no longer needed, because the Minister had just announced that an agreement on the price had been reached with the manufacturer, and Kaftrio would be available for a majority of persons with CF, starting January 1st 2022.

How great was this! Now, the question is: my letter was not published. But it circulated in the e-mail and within the NCFS for two days. It had manifested in Oneness. Did it work anyway? The Universe works in mysterious ways. Information is entangled, it is available beyond dimensions of time and space, non-locally, we know even from hard core physics. Sometimes we get the message regardless of physical limitations. Next to the wonder of life, this is peanuts. I am sure the letter worked anyway and contributed to the decision, even if the Minister never literally read it. Or did he? We will never know.

Now, the letter. Of course this is specific for the Dutch situation. But if you are anywhere in the world where access to live-saving medication is obstructed by slow bureaucracy, by all means, do as I did and write a letter to the appropriate people and institutions in charge. Feel free to use my letter as a template and change it accordingly to your own needs. You never know what will happen.

(to the Minister of Public Health)

Dear Minister, dear Paul Blokhuis,

December the 5th, the year is 2021 *Anno Domini*. Currently you are negotiating the price of the medicine Kaftrio with the manufacturer. An historic occasion.

Perhaps even today you did so again. And after that, you cleaned up your writing desk. So you can start over tomorrow. And again the day after tomorrow.

Then you will be just like all of the 1000 persons with Cystic Fibrosis in the Netherlands who are waiting for Kaftrio. They have to start over every day again too. Because every night their lungs fill up completely and they awaken almost suffocating. Hence they have to cough all day long to clean their lungs from the build-up of sticky mucus. And even so, Cystic Fibrosis will just let them die slowly and grimly.

But they know that one can not negotiate with Cystic Fibrosis. This is something you can learn from them. And almost all European countries know this too, having already allowed Kaftrio for reimbursement in their health system. For this group of patients it is the only available medication for Cystic Fibrosis. Patients have been waiting for this all their (too-short) lives, for generations. You should not extend their suffering. It has gone on for far too long. To continue negotiating would be heartless. And I trust you are not like that at all.

Cystic Fibrosis is not negotiable

You may think this is about money. But persons with Cystic Fibrosis know better than that.

Any further delay will jeopardize their lives even more. This was never your mission. No one ever predestined you for this. And persons with Cystic Fibrosis are not predestined for this either. There are better methods and moments to discuss the price of medicines, without patients having to suffer for that. Every day of negotiations will damage their health and will shorten their lives irreversibly. Young talented people with infinite potential should not die early unnecessarily. Such a loss can't be measured in money. Amongst them is the next Erasmus, Van Gogh, Anne Frank, Multatuli, Johan Cruijff, a daughter and a son, a mother and a father.

Yes, perhaps even a new Paul Blokhuis ("in 2021 he decided on his own authority to provide Kaftrio for all persons with Cystic Fibrosis in the Netherlands"). Dear Minister, you can make history in different ways. But there is only one true way:

Kaftrio should be reimbursed immediately. Starting today. Or else tomorrow. But not a second later. Then you can clean up your writing desk indeed. Persons with Cystic Fibrosis will gladly help you.

Would you please help them to get Kaftrio in return? Then we have a deal!

You can save us.

Breathless we look at you

Expecting your courage and wisdom,

Paul Jordaans, person with cystic fibrosis, Grathem

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PS I use Kaftrio for 4 months now, in a *compassionate use* program provided by the manufacturer. So I know how Kaftrio changed my life. I would love all those with Cystic Fibrosis in our country to have access as well. As of now.