Question for written answer E-001422/2021 to the Commission Rule 138 Virginie Joron (ID)

Subject: Koreans cashing in on French Telethon money

The Telethon n France was born out of the conviction and desire that a cure could be found for illnesses long since regarded as incurable, and for which, sometimes, no research in a cure was even under way<sup>1</sup>. In France, Bernard Barataud, the energetic President of the French myopathy association –'Association française contre les myopathies' (AFM) – organised the Telethon for the first time in 1987 to fund research projects into genetic neuromuscular disorders.

This unique mass mobilisation of volunteers has brought rare diseases out of oblivion and produced a threefold revolution: genetic, social and medical. In 2020, EUR 58 290 120 in donations were collected. Poor people go without so they can give EUR 10. Thanks to these donations, the gene therapy laboratory Yposkesi was set up in 2016 to produce medicines developed by Généthon's research labs.

The Industrie Pharma magazine now reports<sup>2</sup> that the Korean investment holding company SK Holdings has entered into exclusive negotiations with a view to acquiring Yposkesi. SK Holdings hopes to finalise the deal during the first half of 2021.

- 1. Can a business funded by donations and public money be sold?
- 2. The industrial capacities of advanced biotechnologies proved to be insufficient during the COVID-19 pandemic. Given this, is the Commission going to authorise the sale of this up-and-coming industry that is bringing viral vectors under control<sup>3</sup>?

https://www.afm-telethon.fr

https://www.industriepharma.fr/yposkesi-bientot-rachete-par-le-sud-coreen-sk-holdings,115674

https://www.yposkesi.com/innovation/