

OPEN LETTER

Bundesministerium für Gesundheit

(in persona Bundesminister Herr Prof. Karl Lauterbach)

Friedrichstraße 108

10117 Berlin

(Postanschrift: 11055 Berlin)

and

Bundesministerium für Bildung und Forschung

(in persona Bundesministerin Frau Bettina Stark-Watzinger)

Kapelle-Ufer 1

10117 Berlin

Berlin, June 2022

Drug trial at the FAU-Erlangen with the drug BC007 for treatment of Long Covid and ME/CFS

Dear Sir or Madam,

we, as people affected by ME/CFS and Long Covid, were completely deprived of our lives by these among other reasons post-infectious diseases, in case of ME/CFS sometimes even for decades. So far there are no approved treatments. Now that all preparations have been made in Erlangen for the start of the studies, which are very promising for all of us, only the drug is not available according to a report by the TV channel ZDF (www.zdf.de/nachrichten/drehscheibe/medikamente-gegen-long-covid-was-wurde-daraus-100.html). Unfortunately, it is not clear to us what the exact reason is. Is an "admission" or "official approval" missing or can the drug not be provided due to other reasons?

Dr. Bettina Hohberger / University Hospital of Erlangen: "Patients are there. Funds are there. Now we need the drug."

When a promising study, which is financed by the German Federal Ministry of Education and Research (BMBF) for Long Covid and for which people with ME/CFS even contributed some of the funds themselves through a donation campaign (this fact alone has nothing to do with a “welfare state”), is now ready to start after decades of suffering for ME/CFS and approximately two years of suffering for Long Covid, it is another scandal in dealing with both overlapping illnesses if everything is now delayed again for months or even years due to bureaucratic, administrative or other solvable problems.

In addition to politics, we also consider the manufacturer Berlin Cures responsible to engage in a quick solution of the problem. It is not okay to pass the buck to each other at the expense of severely ill people!

The approval of the COVID-19 vaccines, the special assets for the Federal Armed Forces (Bundeswehr) and the building of the LNG terminals in the North Sea show that huge things may also happen faster if they are politically intended.

So please be so kind as to finally meet the responsibilities associated with the urgency and dimension of this humanitarian catastrophe in dealing with ME/CFS and Long Covid and enable the start of the mentioned studies as quickly as possible by approving and providing BC007 for that purpose!

The main concern is to end the infirmity caused by these devastating illnesses of tens of thousands of people in Germany alone and to offer those affected a prospect of participation in life... nothing less !!!

In hopeful anticipation we kindly request your reply to:

info@wir-fordern-forschung.org

Thank you very much.

Yours sincerely,

Sibylle Dahrendorf - Faraz Fallahi - Cornelia Nietzsche - Ilko-Sascha Kowalczyk - Dirk Vogel

Sandra Richter - Timo Strotmann - Ulrike Huf - Birgit Gustke - Martin Hippe

Furthermore, the following people/organizations support this open letter (i.a. in an unchecked list provided online for free entry):

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