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## BMJ INVESTIGATION

# Long covid patients travel abroad for expensive and experimental “blood washing”

Patients with long covid are travelling to private clinics in Cyprus, Germany, and Switzerland for blood filtering apheresis and anticoagulation drugs. Experts question whether these invasive treatments should be offered without sufficient evidence. **Madlen Davies** reports

Madlen Davies *investigations editor*

Gitte Boumeester, a trainee psychiatrist in Almelo, the Netherlands, was infected with SARS-CoV-2 in November 2020. She was tired for weeks afterwards but chalked it up to the virus. Soon, she was experiencing such extreme fatigue that it took her two hours to walk to the kitchen to make breakfast. She had brain fog and heart palpitations, was short of breath, often felt sick, and woke up in the night with chest pain. A battery of tests found nothing wrong with her heart or lungs, and she was sent back to her GP. She left her job in November 2021, after two failed attempts to go back to work.

She joined a Facebook group for patients with long covid, many of whom discussed travel to Germany for apheresis, what some of them call a “blood washing” treatment. Apheresis, in which large needles are inserted into the veins and the blood is filtered, removing lipids and inflammatory proteins, is recommended by the German Society of Nephrology as a standard last resort in the country for lipid disorders. A new clinic offering apheresis for long covid patients, called the Long Covid Center, was opening in Cyprus, and she could be treated there in March. “I thought, what’s the worst thing I’ve got to lose?” she said. “Money was the only thing. I thought, OK, well, why not give it a try?”

Two months later she was back home in the Netherlands, having spent nearly all her savings—more than €15 000 (£12 700; \$15 000)—with no improvement in her symptoms.

Thousands of patients like Boumeester, frustrated at the lack of treatment available for long covid, are travelling to Cyprus, Germany, and Switzerland for apheresis, an investigation by *The BMJ* and ITV News can reveal. Many are also prescribed anticlotting drugs, including clopidogrel, apixaban, and heparin, on a hypothesis that the symptoms of long covid are caused by small clots in the blood that are blocking the flow of oxygen through capillaries. Although some doctors and researchers believe that apheresis and anticoagulation drugs may be promising treatments for long covid, others worry that desperate patients are spending life changing sums on invasive, unproved treatments.

In most European countries doctors can offer experimental treatments or off-label drugs to patients if they believe there is a benefit, explain the risks, and obtain consent. But some experts have criticised

the Long Covid Center’s consent process as unsatisfactory, as it doesn’t make it clear that these are experimental treatments for long covid and the consent form asks patients to sign away their right to sue the clinic if they become injured after having apheresis, which is regarded as a safe procedure.

“It’s unsurprising that people who were previously highly functioning, who are now debilitated, can’t work, and can’t financially support themselves, would seek treatments elsewhere. It’s a completely rational response to a situation like this,” said Shamil Haroon, clinical lecturer in primary care at the University of Birmingham and a researcher on the Therapies for Long Covid in Non-hospitalised Patients (TLC) trial. “But people could potentially go bankrupt accessing these treatments, for which there is limited to no evidence of effectiveness.” Delivering such an experimental treatment should occur only in the context of a clinical trial, he added.

“I am worried these patients have been offered therapies which have not been assessed by modern scientific methods: well designed clinical trials,” said Beverley Hunt, medical director of the charity Thrombosis UK. “In this situation the treatment may or may not benefit them but, worryingly, also has the risk of harm.”

### Spiralling costs

Boumeester spent two months in Larnaca, a port city on the south coast of Cyprus, renting an apartment on the beach. Once or twice a week she would travel to the Long Covid Center for her apheresis and for “add-on” treatments such as hyperbaric oxygen (breathing in oxygen in a high pressure room) and for intravenous vitamin infusions she received at the Poseidonia clinic, a private clinic next door to the Long Covid Center.

The Long Covid Center offers a type of apheresis (heparin induced extracorporeal LDL precipitation or HELP apheresis) where the blood is passed over a heparin filter to filter out unwanted lipids and proteins, a process it says reduces the stickiness of the blood and improves microcirculation. The treatment is normally used as a last resort for patients with lipid disorders that have not responded to other treatments. Needles are put into each arm, and the blood is passed over the heparin filter, separating the red blood cells from the plasma. The plasma is filtered

before being recombined with the red blood cells and returned to the body through a different vein.

Boumeester received six rounds of apheresis, costing €1685 a session, at the Long Covid Center and nine rounds of hyperbaric oxygen costing up to €150 a session, together with an intravenous vitamin drip and a vitamin D injection at €50 each at the Poseidonia clinic. Intravenous glutathione and amino acids were also recommended to her. “I was a little ambivalent about all the extra treatment, but I promised myself if I was there I would do anything, to just try,” she said.

A spokesperson for the Poseidonia clinic said all treatments offered are “always based on medical and clinical evaluation by our doctors and clinical nutritionist, diagnosis via blood tests with lab follow ups as per good medical practice.”

Boumeester was given a treatment memo that advised she start taking an anticoagulation therapy—of aspirin, clopidogrel, and an intravenous infusion of an anticoagulant and an antiviral—up to twice a week. It advised her to buy three months’ worth of these drugs before she left.

Boumeester was also advised to buy two weeks’ worth of clopidogrel and 10 days’ worth of hydroxychloroquine as an early treatment package in case she was reinfected with SARS-CoV-2, despite a Cochrane review published in March 2021 concluding it was “unlikely” that hydroxychloroquine had a benefit in the prevention of covid-19.<sup>1</sup> Additional over-the-counter supplements and a ketogenic diet were also recommended.

Apheresis, and the associated costs of flying across Europe over weeks or months, is so expensive that patients are setting up fundraising pages on websites such as GoFundMe to raise the money.

“I’d have sold my house and given it away to get better, without a second thought,” said Chris Witham, a 45 year old businessman from Bournemouth who spent around £7000 on apheresis (including travel and accommodation costs) last year in Kempten, Germany. The treatment did not improve his long covid symptoms, but six patients told *The BMJ* they felt better after a few rounds of the treatment, although none were cured of all their symptoms.

## Informed consent

Boumeester was asked to sign a consent form at the Long Covid Center before undergoing apheresis, a form lawyers and clinicians described as inadequate. As well as being full of spelling mistakes, grammatical errors, and half finished sentences, it asks patients to waive any claims that they might have against the Long Covid Center and employees for “any personal injury, loss or death arising from the resulting of this treatment.”

Under English and Welsh law this clause would be invalid, said Daniel Sokol, a barrister at the 12 King’s Bench Walk chambers in London and a medical ethicist. “You can’t say, ‘By the way, you agree not to sue us if we cause you horrible injury or kill you, even if it’s through our own negligence,’” he said. “You can’t do that.”

The form lists contraindications in technical language and asks patients to declare that they are medically fit to undergo the treatment. “These are questions that should be answered by the clinician,” said Sokol. “I don’t think you can put that onus on the patient.”

Sokol voiced a concern that the form’s description of apheresis as a “unique therapeutic option with clear advantages” may overstate the benefits for patients with long covid. He said, “What’s important

in these cases is to communicate to the patient the experimental nature of the procedure and the fact that there is quite a lot we don’t know about the effectiveness of it, and indeed also about the risks, the complications, the side effects with patients who have long covid, as opposed to patients who may have cardiovascular issues.”

“I do think they should emphasise the experimental nature of the treatments more, especially because it’s so expensive,” Boumeester said. “I realised before I started that the outcome was uncertain, but everyone at the clinic is so positive that you start to believe it too and get your hopes up.” The Long Covid Center did not respond to these criticisms.

*The BMJ* contacted Cyprus’s Ministry of Health and the Cyprus Medical Association to ask whether the clinic or doctor were breaking any professional or ethical standards in the country but did not receive a response.

## Success stories on social media

Boumeester decided to travel to Cyprus after reading testimonials and research on the website and Facebook page of the Apheresis Association, a group with 4700 members that promotes apheresis as a treatment for long covid. The association was set up and is run by an Austrian businessman, Markus Klotz, who also set up the Long Covid Center in Cyprus.

The association coordinates appointments at clinics across Europe that offer the treatment and acts as a patients’ forum. Moderators post positive statements about apheresis as a treatment when only anecdotal evidence exists. “Over 80% of patients report to keep their gains permanently,” one post read. “There are no known risks,” said another. *The BMJ* contacted the Apheresis Association but did not get a response.

Klotz decided to set up the Long Covid Center after having had the condition himself and trying a range of treatments, including HIV medication, antivirals, and supplements. He flew to Mülheim, west Germany, for apheresis and anticoagulation therapy after hearing Beate Jaeger, who runs the Lipid Center North Rhine, talking about the treatment on the radio.

Jaeger, an internal medicine doctor, told *The BMJ* that in March 2020 she read reports saying that covid causes problems with blood clotting. Apheresis is a standard treatment in Germany for patients with lipid disorders that have not responded to drugs, and she believed that the HELP apheresis treatment she had used for decades to treat patients with cardiovascular illnesses could help those with long covid.

She talked to colleagues, hoping they would allow her to treat covid patients in intensive care wards in Germany, but was denied permission, and tried to get her hypothesis published in a German medical journal, but was rejected. In February 2021 the relatives of two of her cardiovascular patients who had been suffering from long covid agreed to undergo HELP apheresis. Jaeger said their symptoms improved after just a few sessions.

She treated around 60 patients for free, to see if she was on the right track or not, and found the treatment “extremely successful.” She told *The BMJ* she has now treated thousands in her clinic, with success stories spreading on social media and by word of mouth.

She treats long covid patients with HELP apheresis, which she says reduces the viscosity of the blood and improves organ perfusion. She also offers plasmapheresis, which filters autoantibodies out of the blood, and regularly puts patients on a triple anticoagulation treatment made up of drugs including aspirin, clopidogrel,

apixaban, heparin, and dabigatran, with patients flying back to Germany periodically for prescriptions.

In case reports and television interviews,<sup>2,3</sup> Jaeger said she had had patients with long covid who came into the clinic in a wheelchair who were able to walk after the treatment and people who couldn't walk who became able to jog. Clinics around the world are copying her methods. "There are now many centres in Germany following me, centres in Switzerland, a centre in Turkey is starting. I think Italian centres have started," she said.

Jaeger accepts that the treatment is experimental but said trials take too long when the pandemic has left patients desperately ill. "If somebody is desperately sick and you have no other way out, you are allowed to treat him if he agrees to treatment," she said. "And the patients I have treated, they have agreed to treatment, and their profit is a lot."

She said she has also tried to weather the expense of the treatment for her patients, allowing a British printer to live in her house for weeks, for example, and refusing to take money from patients who are spending their life savings. The North Rhine Medical Association, which examines whether doctors have violated their professional code of conduct, told *The BMJ* it has not received any complaints about Jaeger or her clinic from patients or other organisations but will investigate if it does.

## The evidence

Jaeger and Klotz point to research by Etheresia Pretorius, a professor in physiological sciences at Stellenbosch University, South Africa, to justify treating long covid patients with apheresis and triple anticoagulation therapy.

Pretorius's group has published a peer reviewed study, review articles, and preprints that hypothesise that "microclots" present in the plasma of people with long covid could be responsible for most long covid symptoms.<sup>4-6</sup> Stellenbosch University has filed a provisional patent for Pretorius's method of detecting microclots through fluorescence microscopy,<sup>7</sup> and her laboratory is working on a diagnostic tool that could detect microclots and be rolled out in hospital pathology laboratories worldwide. A fundraising page set up by supporters has raised \$161 000 to support the project.<sup>7</sup> Jaeger has bought a €200 000 microscope for her clinic and pays licence fees to Stellenbosch University for use of its method.

But experts contacted by *The BMJ* said that more research is needed to understand how microclots form and whether they are causing long covid symptoms.

"They [microclots] may be a biomarker for disease, but how do we know they are causal?" said Robert Ariens, professor of vascular biology at the University of Leeds School of Medicine. He believes the clinics offering apheresis and anticoagulation therapy are prematurely providing treatment that is based on a hypothesis that needs more scientific research. "If we don't know the mechanisms by which the microclots form and whether or not they are causative of disease, it seems premature to design a treatment to take the microclots away, as both apheresis and triple anticoagulation are not without risks, the obvious one being bleeding," he continued.

There is as yet no published and peer reviewed evidence showing that apheresis and anticoagulation therapy reduce the microclots. "As we don't know how they form, we cannot tell if this treatment will stop microclots from recurring," Ariens said.

In June 2022 the German Society for Nephrology (DGfN), the organisation that writes the guidelines on apheresis in Germany, said case reports were sufficiently motivating to warrant controlled

trials but no recommendation could be made about apheresis or immunoabsorption, a similar process in which autoantibodies are filtered from the blood, until scientific data had shown benefit.

"Currently, these therapies are offered on a self-pay basis by a number of centres, including those from non-medical specialties such as naturopathy, with the support of primarily commercially driven interest," said Volker Schettler, head of the DGfN's commission for apheresis. "The DGfN calls for randomised controlled trials on the benefit of apheresis therapy in these patients," he said.

Jaeger told *The BMJ* that carrying out a randomised controlled trial would be ideal but that she does not have the money. "It costs millions," she said. "I'm not rich enough to do it, unfortunately." She has tried to persuade companies to fund trials and has set up an international research collaboration looking into treatments for long covid.

She said she is angry about "dogmatism" in medicine. "So, this is a cruel, horrifying disease. And we have to act on this," she said. "If I see a child in a wheelchair suffering for a year, I prefer to treat and not to wait for 100% evidence. . . . There is never a treatment without risk in medicine. But I've been working my whole life on sky high risk patients. And I saw in this treatment it did no harm."

## Follow-up care

Some clinicians are concerned about the lack of follow-up care for patients when they leave clinics that offer apheresis. Anticoagulation should be given in a supervised way by clinicians who regularly follow up patients, because bleeding could present as bruising or nosebleeds but could also be a brain haemorrhage, said Amitava Banerjee, a cardiologist in London and chief investigator on the Stimulate-ICP trial into long covid. "I'm concerned that this has been pushed in a vulnerable group," he continued. "We haven't got solid evidence for single anticoagulation therapy, let alone triple."

A triple anticoagulation regimen can have "devastating consequences" if someone falls or has an injury, said Benjamin Abramoff, director of Penn Medicine's Post-Covid Assessment and Recovery Clinic in Philadelphia.

Jaeger said she trains patients to look for the signs of bleeding, provides them with a passport detailing their drug regimen, and gives them a letter for their GP, sometimes trying to contact the GP directly. Patients from the UK and Denmark told *The BMJ* that doctors in their home countries refused to prescribe such regimens.

Klotz told *The BMJ* that prescriptions are individually assessed by the clinic's doctor. "We as a clinic neither advertise, nor promote. We accept patients who have microcirculation issues and want to be treated with HELP apheresis," he added.

## "Too long to wait"

Some patients debilitated by long covid say they can't wait years for the results of trials. Asad Khan, a respiratory doctor in Manchester who has long covid, said doctors should consider off-label prescribing of drugs such as anticoagulants after an informed discussion with the patient about risks and benefits. "We need to get out of this slavish adherence to guidelines," he said. "Doctors need to grow a bit of a spine and just go, OK, others have done this. They've found it helpful. Let's think outside the box and offer a trial of treatment to the patients and see if they benefit from this."

Khan speaks about his experience of apheresis on television interviews and in YouTube videos, after receiving 21 rounds at

Jaeger's Mülheim clinic, which he said improved his symptoms greatly. He has spent nearly £40 000 on apheresis, private prescriptions, including triple anticoagulation therapy, and other complementary treatments such as cranial osteopathy and breath work for long covid.

"All these rules about evidence based medicine and trials, they all go out the window when you're facing a future in a darkened room and a life of disability," he said. He wants to see research being carried out more quickly. "Nobody should have to travel abroad for treatment using their life savings," he said.

Competing interests: [bmj.com/about-bmj/editorial-staff/madlen-davies](https://www.bmj.com/about-bmj/editorial-staff/madlen-davies).

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**Correction: The sum spent by Gitta Boumeester was €15 000 (not the €50 000 originally stated). We corrected this on 13 July 2022.**

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