Who contacted us?
We were contacted by phone by the grandfather of a young CF patient living in Barbados.

What was the request?
The patient required access to a prescription inhaled antibiotic which is approved in the US but not in Barbados.

How did WEP Clinical proceed?
We contacted the drug manufacturer and requested access on behalf of the patient. The manufacturer kindly agreed to provide the drug free of charge for a one year period, after which they would reassess.

What were the next steps?
The next steps were two-fold:
We worked with the patient’s physician in Barbados as well as the physician he visits biannually in Miami, US, to get all the necessary paperwork. We also contacted the Barbados Drug Service to get the necessary importation documents.
We then worked with the manufacturer and its shipping partner to organize the shipment of the cold-chain product.

What was the outcome?
We had the drug shipped out to Barbados in May, 2017.
Who contacted us?

We were contacted by a representative of the advocacy group who had been asked to help a physician in Egypt.

What was the request?

The physician was requesting access to a potassium channel activator for one of her patients who suffers from hyperinsulism. The drug is approved and readily available in Europe but not in Egypt.

How did WEP Clinical proceed?

Through our offices in London, UK, we are able to source and purchase the drug on the patient’s behalf.

What were the next steps?

We worked with the physician to contact the Egyptian Drug Authority (EDA). EDA told us that we would require a local Egyptian agent to clear the drug through customs. We got in contact with a local Egyptian customs agent and worked with him to organize the collection of the drug.

What was the outcome?

We shipped the drug successfully to the patient and are now working on the next three month supply.
Who contacted us?

We were contacted by a representative of the advocacy group who is also a Pompe patient.

What was the request?

Pompe patients in New Zealand have limited access to treatment because there are currently no approved Pompe drugs in the country. The patient wanted us to work with her to contact pharma companies around the world to request access to their investigational or approved drugs.

How did WEP Clinical proceed?

We contacted several companies on the patient’s behalf including Sanofi Genzyme, BioMarin, Amicus Therapeutics, and Audentes.

What were the next steps?

We had the most success with Sanofi Genzyme whose drug, Myozyme, is available in the US and Europe but not in New Zealand. The company informed us that they were working with the national health service in New Zealand to negotiate access for the patients. But when the negotiations were unsuccessful, we continued to advocate on the patient’s behalf.

What was the outcome?

Sanofi Genzyme has agreed to provide Myozyme to four of the ten Pompe patients in New Zealand through an International Charitable Access Program (ICAP).
Who contacted us?

We were contacted by a representative of the advocacy group.

What was the request?

ULF has been working to try and help Leukodystrophy patients in the US gain access to Lorenzo’s Oil. This Oil is available as a food product across-the-counter in Europe but is considered a drug in the US and is not available to patients.

How did WEP Clinical proceed?

We got in contact with a physician who is currently helping a limited number of patients access the oil through a treatment IND. He informed us that he cannot continue to do this indefinitely and cannot help all the new patients that are coming forward.

What were the next steps?

We worked with the physician and FDA representatives to come up with a working solution that could help patients in the US access Lorenzo’s Oil. We looked at changing the Oil to a food product, rather than a drug, but that was not feasible, so we continued to explore other options.

What was the outcome?

We found a solution whereby we work with patients to help them import the oil into the US on a personal use basis, which allows them to access a 3-month supply at a time.
The British Dupuytren’s Society

Who contacted us?

We were contacted by a representative of the advocacy group.

What was the request?

Dupuytren’s patients in the UK are unable to access certain treatments that are available in the US, so the organization wanted to see if we could help them with this issue in any way.

How did WEP Clinical proceed?

One of the treatments the organization wants to access is a compounded drug manufactured by a company in the US. We got in touch with this company to see if there was anything that could be done to provide access to Dupuytren’s patients in the UK.

What were the next steps?

The company is willing to supply the drug to us, which will then allow us to supply it on to patients in the UK, after we receive a prescription from a physician. We are now working with the company to formalize this agreement.

What was the outcome?

We are hopeful that we will be able to start supplying patients in the UK with this treatment in the coming months.