A FAIR PRICE FOR THE LIFE-SAVING PERTUZUMAB DRUG

Pertuzumab (brand name Perjeta) is an effective breast cancer drug but the manufacturer, Roche, is charging a price so high – over £40,000 - that NHS Scotland can’t afford it. As a result Scottish cancer patients are missing out on a medicine that could give them vital extra months of life – or trying to find the tens of thousands of pounds needed to pay for it themselves.

What are you calling for?

The drug company, Roche, are able to demand this extremely high price because they have a monopoly meaning no one else is able to make or sell the medicine. But when companies abuse their monopoly like this there are legal safeguards designed to protect public health, and to make sure patients’ lives come before pharma company profits. One such safeguard is known as a Crown use licence. It allows the government to give permission to another manufacturer to make and supply the drug to the NHS at a price we can afford.

With Roche making billions of pounds in profits every year, and Scottish cancer patients dying without access, we are calling on the Scottish government to use their power to break Roche’s monopoly and ensure every patient that needs pertuzumab can get it.

What is a crown use licence?

When a new medicine is developed drug companies usually apply for a patent. This gives them a twenty year monopoly during which time no one else can make or sell the medicine.

The global rules around patents are set out in a World Trade Organisation agreement known as TRIPs (Trade-related Aspects of Intellectual Property Rights). When it was agreed, governments realised that the rules within TRIPs could prevent people from accessing the medicines they need, so they built in a safeguard to ensure patents didn’t prevent people from accessing treatment.

One of these safeguards is known as a compulsory licence – or in UK law a Crown use licence. This law gives the government the power to grant another manufacturer permission to produce an identical copy of a patented medicine. It is designed to stop drug companies from abusing their monopoly by charging unaffordable prices.

Dunise’s story
Dunise, pictured above, is a Scottish breast cancer patient living in England. She is unable to move home to be with her family because the drug pertuzumab is not available in Scotland. Right now, women like Dunise are having to choose between treatment and being with their loved ones. Sign her petition here: justtreatment/dunise

Has a Crown use licence been used in the UK before?

Yes. In 1991, the UK government authorised the supply of machines known as lithotriptors, for treating kidney stones, under the Crown use provisions of the Patent Act 1977. In 1995, the UK Department for Health raised the possibility of using Crown use

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provisions on pharma company Chiron’s hepatitis C (HCV) diagnostics. Chiron acknowledged the pressure that this placed on them to voluntarily licence.

Kirsty’s story

Kirsty, pictured left, lives in Edinburgh. On receiving a breast cancer diagnosis in 2017, she was told that she would need pertuzumab prior to surgery. As this drug is not available in Scotland, Kirsty had to enlist the help of friends and family to pay £10,500 for the three doses of the drug she needed.

Didn’t Roche spend loads developing the drug?

Pharmaceutical companies are cagey about the true research and development (R&D) costs of bringing a new drug to market, making it very hard to know what is actually spent on a drug’s development. There is a huge lack of transparency around the issue, and pharma industry claims that it costs $2.6bn to develop a new drug have been widely discredited.

Non-profit research and development organisation the Drugs for Neglected Diseases Initiative (DNDi) say that it costs a maximum of €150m to develop a new chemical entity.

In the case of pertuzumab, the basic research underpinning the drug was funded by the UK taxpayer. So right now we’re paying twice – first for the initial development, then to buy back the drug at a hugely inflated price.

What’s more, Roche are making a killing out of his drug: pertuzumab generated sales for Roche of £1.44bn in 2016 alone and these sales are expected to grow to £3.5bn a year by 2020. In the same year the CEO of Roche, Severin Schwan, received a pay package of £8.9m.

Who would benefit from this drug?

Around 426 patients in Scotland could benefit from the drug each year through neoadjuvant (pre-surgery) use. Between 244 and 983 patients could benefit from the drug each year to treat metastatic breast cancer. All these patients are currently being denied access.

What has happened so far in the negotiations between Roche and the Scottish Medicines Consortium (SMC)?

In December 2016 the Scottish Medicines Consortium (SMC) – who make decisions on medicine approvals for NHS Scotland – rejected pertuzumab for neoadjuvant use because of the high price. In June 2017 the SMC turned down pertuzumab for metastatic breast cancer for the third time because of a lack of cost-effectiveness.

What’s the situation in the rest of the UK?

Roche offered a secret discount on the price to NICE, the body that approves medicines for NHS use outside Scotland, securing approval for the NHS in England for neoadjuvant use in 2016. They agreed another secret deal for the drug to be used for metastatic breast cancer in February 2018. Prior to this it was only available through the Cancer Drugs Fund. The decision to make the drug routinely available on the NHS should lead to availability across Wales and Northern Ireland as well.