

Dear Ms Marcalo

Re: Risks of an epileptic seizure

As chairman of the UK's leading epilepsy charity, the National Society for Epilepsy (NSE), I am asking you, the Arts Council and the Bradford Playhouse to think again about plans for a 24-hour performance at the Bradford Playhouse, during which you hope to induce an epileptic seizure.

Ms Marcalo, you are trying to do something brave for people with epilepsy and we salute your courage and respect your freedom of expression. We do want to make sure, however, that you are all going ahead on the basis of the full information.

There is great danger in coming off medication that controls epileptic seizures and then setting about provoking a seizure. In these circumstances, the seizure could be more serious than expected, risking real danger to your health. In rare circumstances a sudden seizure can even lead to sudden unexpected death from epilepsy (known as SUDEP). SUDEP, although rare, is sometimes associated with people who suddenly stop taking their medication.

Ms Marcalo, you have said that you plan to stop taking your anti-epileptic drugs. This is something that should only be done under medical supervision and should be closely monitored. Can I emphasise again that you are putting your health at serious risk.

Also, coming off anti-epileptic drugs (AEDs) and then returning to them following a seizure may mean that the AED you have been taking before may not control your seizures as well afterwards. This could have a major and ongoing impact on your state of health and, consequently, your work and life.

I wonder if you have considered that this act may encourage people, particularly young people, to follow your example, which could have tragic consequences.

Creating seizure-provoking conditions e.g. strobe lighting could also lead any other people in the audience with epilepsy to experience an epileptic seizure. I am sure the Bradford Playhouse has made preparations for this outcome and has expert first aid arrangements in place, but I should like to emphasise how important it is to warn people attending the show of the risk they could be taking.

There is also the question of privacy. You are encouraging people to take photos of yourself having a seizure with their mobile phones. But people may also take photos of others in the audience having an unexpected seizure sparked by these conditions. Such images can often find their way onto the internet and can affect people's lives in unexpected ways. I think the Bradford Playhouse would need to warn the audience of this possibility.

I would like to reiterate that I respect this is your personal decision, but I urge you to consider the information in this letter.

Yours sincerely

Eileen Springford
Chairman
National Society for Epilepsy