

A tale of risk

Each drug has its own story.

Some are fine tales of discovery: the discovery of a rare or not so rare disease, its serious or not so serious consequences, its natural course and causes, and then an effective treatment. In the best stories, the treatment benefits numerous patients for a very long time, its risks are considered acceptable, and the price society pays for it is fair.

Often though, it's an everyday story of markets, target populations, territories, influence, and so on, hard fought for and won. In short, a story that revolves around money...

And for some drugs, the story ends.

Perhaps the drug was withdrawn from the market, pulled discreetly and silently from the shelves, even though such decisions often indicate that the drug was more dangerous than beneficial, or that it was no longer sufficiently profitable. Or it might go out with more of a bang, with those who promoted the drug facing justice for the public health disaster it caused, and those responsible having to explain themselves in court. Sometimes the end was premeditated, to insidiously orchestrate the imminent arrival of a new drug, to fabricate a need or manufacture a shortage.

What do these stories have in common? They all revolve around the same main characters: patients.

It is patients who live with the disease and all of its consequences. It is patients who form groups to have their voices heard and to advance research. It is volunteers and patients who contribute to research by participating in preliminary studies, then in clinical trials, their bodies used to experiment with new substances, with no certainty whatsoever over the nature of the effects these substances will produce. It is patients who describe, or sometimes report, unexpected or serious adverse effects. Effects that may have severe sequelae, even when the drug responsible has been withdrawn, or even end in tragedy for some patients and the family and friends they leave behind.

Whatever the drug, its story and how it is told, it is always patients who are exposed to the risks of diseases for which no acceptable treatment exists. But it is also patients who are exposed to the risks of inadequately evaluated drugs.

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