

## Advocates, Let's Make It Our Problem!



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Inspire2Live has been created to empower people to convert the sense of powerlessness, caused by cancer, into one of strength. Inspire2Live is founded on the absolute belief that one can attain the greatest possible satisfaction by putting their heart and soul into helping others. Its motto is "Never, ever quit!"

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I have lymphoma. Is that my problem or that of my physician? Or perhaps the problem of research and industry? It is indeed my problem and I need my physician badly. She can only do her work when good science is being done and when the healthcare industry provides her with the right treatments. There is a lot of work and cooperation that needs to happen, but it is still very much my problem.

I think most patient organisations are ill-equipped and too modest. They can and need to do better. Patient advocates need to stand up and demand to be at the table where discussions are taking place and decisions are being made. It is our problem as patients, because it is our risk and our lives that are at stake. Isn't it strange that we're not involved in discussions about solutions and that we're not consulted about decisions where we, in the end, are the ones who need to decide? Is it not wrong that we are not at the table?

"If you're not at the table, then you're on the menu!" It's as simple as that. I've written about it before, but healthcare is often about money for some of the other stakeholders e.g., "the more patients, the better", doing research, developing and giving treatments, setting up and applying regulations. Only fellow patients and patient advocates can represent the patient. No-one else. We are the patient's voice in cancer. It is about time that we are taken seriously.

Not that I think there is bad intention in healthcare. On the contrary. Every now and then there will be a bad doctor or is someone in industry who is maybe not working for the benefit of the patients, but in general we see that everyone is working for the same good cause. However, cooperation is lacking in most situations. Patient organisations, physicians, researchers, industry, regulators, governments, payers all do good

work, but in general, they do it on their own. This is exactly why patient advocates need to take their responsibility and play their role. No-one else will do this because no-one else derives any real benefit from the cooperation, but patients and society most certainly will.

Physicians need to treat patients, researchers need to do good research, industry needs to sell treatments, regulators need to produce regulation, payers need to pay, patients need to be treated and governments need to facilitate all of the above. The problem with patients, however, is that they are dependent on all these stakeholders and dependency creates a situation in which it is difficult to stand up and demand better treatments or transfers to a hospital specialised in their type of cancer. There are no bad hospitals but some hospitals are simply better than others in treating certain types of cancer.

It is different for patient advocates who are, or at least should be, independent. No strings attached. Therefore, patient advocates need to stand up and represent the patients. And as for being taken seriously, we need to know what we are talking about. Discussing the biology of cancer means that patient advocates have to know about molecular biology. Giving the right treatment to the right patient at the right time means that we have to know everything about treatments. Both; existing treatments (including very old medicines with which we can achieve a lot thanks to drug repurposing) and newly developed treatments, without forgetting low- and middle-income countries which also need safe, effective and affordable treatments. We cannot leave 6.2 billion people out of the equation.

When we say that "we are the patient's voice in cancer", it means that we know more than enough about what we are talking about to be taken seriously and we demand to sit at every table where decisions are being made. Because at the end of the day, we are the ones taking the risks and it are our lives which are being discussed. And that is most definitely our problem.

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