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Patient Issues: Banned!

Oliver K

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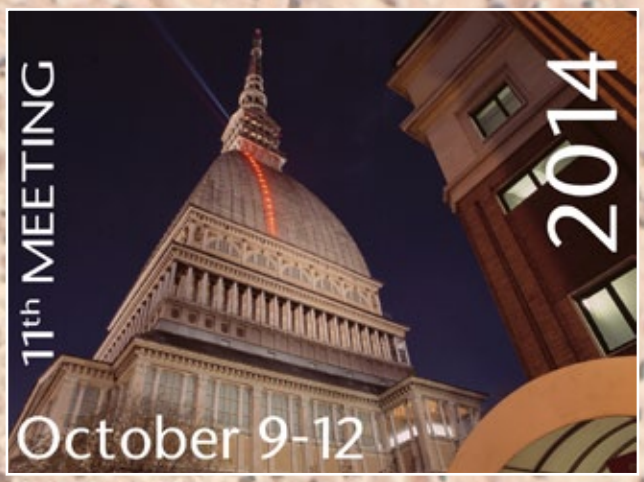

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Banned!

Kathy Oliver

Overzealous, overprotective, and anachronistic legislation forbids patient advocates access to information and networking at one of the world's major cancer conferences.

Cancer patient advocacy – including important work by advocates in the brain tumour community – is now a well-established, respected movement in Europe.

After years of dedicated, determined work, patient advocates are finally becoming accepted as equal stakeholders in the multidisciplinary cancer setting. In the brain tumour world, this is vital as there is so much which needs to be done to serve our patients well during their journeys.

Patient advocates participate as advisors to pan-European academic institutions and global pharmaceutical companies. They are members of important committees at august medical societies. They contribute wise insights to regulatory, pricing, and approval bodies.

Patient advocates share the plenary podium at international conferences with the best clinicians and researchers in the world and deliver high-quality presentations to auditoriums packed with medical professionals, journalists, key opinion leaders, and politicians. They often work exhausting hours, travel tirelessly from country to country raising awareness of cancer, master complex scientific theories, lend their expertise in various fora, and frequently do all of this on a purely voluntary basis.

Importantly, patient advocates also serve as delegates at many medical conferences. In busy exhibition halls, they meet with the pharmaceutical industry to discuss the latest promising cancer therapies and to learn what is in the companies' pipelines that might be relevant to their disease-specific populations.

One of the crucial aspects of medical congresses is the free flow of information between patient representatives and the pharmaceutical industry.

Patient Advocates Refused Entry

But one autumn day in September 2013, patient advocates found themselves relegated to the outside of the barriers that wound their way around the vast exhibition hall at the European Cancer Congress (ECC) in Amsterdam, forbidden to enter this area and stymied in their efforts to access information hitherto always available to them at these types of events[1].

[1]The European Cancer Congress (ECC) is organised by the European CanCer Organisation (ECCO), European Society for Medical Oncology (ESMO), and European Society for Radiotherapy and Oncology (ESTRO) in partnership with the European Society of Surgical Oncology (ESSO), European Association for Cancer Research (EACR), European Oncology Nursing Society (EONS), and the European Society for Paediatric Oncology (SIOPE). See http://www.ecco-org.eu/

Cancer patient advocates mounted a dramatic but dignified protest at the ECC and signed a petition stating their strong objections to anachronistic and unnecessary regulation. Photo courtesy of Jan Geissler, ECCO Patient Advisory Committee.

There was suddenly – after years of unfettered access to conference exhibition halls – no chance to interact personally with companies, no on-the-spot exposure to new pharmaceutical information about promising therapies. It was a real blow, a retrograde step back to the days when the patient community was seen, but never heard.

Why the Discrimination?

Article 86 of the 2001 EU Directive 2001/83/EC prohibits advertising and promotion of prescription-only drugs to the general public. The article requires that promotion of drugs must only be to those who are qualified to prescribe and supply medicinal products [1].

The Dutch Medicines Act (DMA) incorporates this Directive within its country's law and the Dutch Healthcare Inspectorate – which is responsible for overseeing compliance with the DMA – recently extended the enforcement of the DMA to international medical congresses. However, for some reason neither Dutch conference venues nor conference organisers were made aware of this fact [2].

Once the European CanCer Organisation (who were running the ECC) heard about the legislation, they were stuck between a rock and a hard place. With their congress occurring in September (some few months after hearing the news) there was not enough time for industry to change their booth set-ups to accommodate different types of visitors (for example setting aside a private part of the booth for prescribers only). Nor was there sufficient time to redesign the whole exhibition layout.

The only feasible solution, the organisers felt, was to badge participants as either "prescribers" or "non-prescribers" which is what happened.

Other Professionals Left Out

Not only patient advocates but also non-accredited journalists, professional medical society staff, and others were also banned from the exhibition hall because they were non-prescribers.

What is more, a major exhibition such as the European Cancer Congress includes not only pharmaceutical companies but the booths of medical publishers, professional societies, pre-clinical and research groups, nursing organisations and a range of other non-pharma stakeholders. Access to these displays – because they were in the exhibition hall – was also banned to non-prescribers.

As Jan Geissler, one of Europe's leading cancer patient advocates said: *"Exhibitions like these have been a key meeting point for all stakeholders for many years, across many countries. Patient advocates attend in their capacity as experts; most of them are members of government committees, regulatory authorities, research groups, and healthcare advisory boards. They are not just participants informing themselves about drugs, but they provide a platform for discussing all kinds of services for their constituents. Patient advocates must be entitled to access all information as equal stakeholders in healthcare."*

Patient Advocates Are the Crucial Link

Patient advocates occupy a privileged position. They are the vital conduits between patients in the general public and drug developers and other parties. Congresses like the ECC are not attended by members of the general public but rather by groups of professionals – be they medical experts, allied healthcare workers, researchers, or indeed patient advocates. All of these groups need the information available from the exhibition hall.

Davi Kaur, Head of Congress Unit at the European CanCer Organisation in Brussels who helped organise the European Cancer Congress in Amsterdam, points out: *"Our philosophy for the congress has always been that it is open to professionals only who have an interest in cancer. It is a closed and regulated environment, which ensures that there is always a fair exchange of dialogue between all stakeholders ... [so] to impose restrictions in a closed environment makes no sense"* [3].

Advocates Protest

Patient advocates are neither shy nor retiring, nor ever at a loss for making a strong point.

So in response to the ban at Amsterdam, cancer patient advocates mounted a dramatic but dignified protest at the ECC and signed a petition stating their strong objections to what was seen as anachronistic, outdated, insulting, and unnecessary regulation.

Imposing EU Directive 2001/83/EC in the manner seen in Amsterdam is a dangerously retrograde step which stifles communication and flings professional advocates back to a time when patients were only considered subjects of care, rather than active and well-informed partners in their own disease journeys.

Ironically, some of the information which would have been available to patient advocates in the exhibition hall at the ECC was already freely available on the internet.

Future Worries

What happened in Amsterdam may only be the beginning of this very worrying trend in discrimination within the closed environment of medical conferences.

Organisers of major international medical congresses in Europe are at this very moment reviewing their plans for future events and will undoubtedly become far more selective in their choice of country and venue.

As Davi Kaur says: *"This would mean that local and national doctors, nurses, and researchers would miss out on the opportunity to be educated by high-level global experts at low cost."* Additionally, she notes: *"The economic value in bringing a congress to a city and country is high"* [3].

As for patient advocates?

Never a group of campaigners to tolerate inequity, they are fervently urging all stakeholders in the cancer journey to impress upon their governments their objections to the unacceptable face of discrimination and exclusion which existed at the ECC.

There is also the fear that being banned from exhibition halls at scientific conferences today could result in far-reaching consequences tomorrow. We may find that further legislation building on that which exists already will see patient advocates forbidden to contribute to medical journals, denied access to crucial information on the internet, banned from academic and industry advisory boards, and barred from a range of other important activities, all of which they do altruistically.

Shunting patient advocates off to a peripheral corridor and shutting the exhibition doors against them denies access to a crucial stakeholder.

After all – whether patients, patient advocates, medical professionals, or industry, we are all waging the same battle against cancer. We must do this together, not apart.

References:

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Correspondence to:
Kathy Oliver
International Brain Tumour Alliance
PO Box 244, Tadworth, Surrey KT20 5WQ, United Kingdom
e-mail: kathy@theibta.org