

Gary Bain's precepts for chronic obstructive pulmonary disease patient groups

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Submitted Mar 23, 2015. Accepted for publication Mar 23, 2015.

doi: 10.3978/j.issn.2072-1439.2015.04.24

View this article at: <http://dx.doi.org/10.3978/j.issn.2072-1439.2015.04.24>

Our colleagues from Emphysema Foundation for Our Right to Survive (EFFORTS), whose article is published in this issue of the International COPD Coalition (ICC) Column, are part of one of the most active and successful of all the US COPD patient groups (1). They truly involve COPD patients and their families in their educational and advocacy efforts. They have continuously had thousands of COPD patients actively participating in their group since the 1980s. Their article modestly puts forward their programs and goals.

Unlike many COPD patient organizations in the US, which have few COPD patient members and only function as companies that sell educational programs or else carry out promotional and marketing campaigns for pharmaceutical companies, EFFORTS's large COPD patient membership is networked together in a way that educates and benefits the patients, mainly through internet communications. COPD patients are often limited in their travel and activities; the internet is a boon to their efforts to learn, share, and improve their lives. Gary Bain, a COPD patient and an individual with high-tech knowledge, was the person who first implemented digital media for COPD patients on a large scale.

I remember during the early days when the US COPD Coalition was being established, I first talked with Gary Bain, the founder of EFFORTS. He gave me precepts to follow in managing a COPD patient organization, and he ordered me never to violate them. The first lesson was the importance of using the internet to communicate. Gary was very excited about what the internet could do to facilitate communication among COPD patients. He was an accomplished organizer and patient advocate, and he involved thousands of COPD

patients, their families, and other interested individuals in the EFFORTS communications. He invited me to join their internet messaging service just to see how active the members were. EFFORTS had a primitive link serve network in those early days, but it satisfied their needs for communication. I was added to the list and each day I received more than 300 messages from EFFORTS members until I finally asked to be taken off the list because it overwhelmed my email.

Internet communications are even more important for a global organization such as the ICC because of our global membership. As we have previously published in the ICC Column, many international patient groups have very limited resources and meeting in person with group leaders from around the world is seldom or never possible. For ICC, internet communication and a column in a global, open access medical journal such as the *Journal of Thoracic Disease (JTD)* that reaches professionals involved in thoracic disease care are the ideal ways of permitting frequent, in-depth communication among COPD patients, COPD-treating-physicians, and patient advocates.

Gary's second lesson for me was his strong belief that patient organizations must be non-profit and that the leaders of the organizations should be volunteers and not accept a salary or other funds for their work. He pointed out that most of the leaders of respiratory patient organizations in the US were oriented solely to fund-raising for their own benefits and as a result their organizations acted to serve the sponsors that supplied their funds. The COPD patients were exploited by the organizations and rather than being benefited, they were damaged by the misinformation that they received because of the patient groups' efforts to market their sponsors' products for them. He did realize

that for larger patient organizations there would have to be some paid staff, but his ideal was that the leaders of a group should be deeply motivated by the cause they were serving and not operating to promote their self-interests.

I found that Gary was also right in his third precept about not letting financial conflicts of interest influence the goals and activities of patient organizations. All too often such organizations solicit money from commercial sponsors and put forward the sponsors' messages as if it were their own. Patients are always the losers in such a transaction. In the US, most patient organizations conceal the payments they receive from commercial organizations to promote their products. It is for this reason that ICC, Inc. (a not-for-profit corporation registered in the US) adheres to and publishes on its website its commitment not to accept funds from commercial organizations, does not spend money on fund-raising, and that none of the ICC leaders receives any payment for their work on behalf of COPD patients.

It is always informative to look through the websites of various patient organizations to see if they reveal the sources of their funding and their payments to their leaders. Almost none publish or publicly reveal such information for just the reason you would suspect. A sad fact is that most of the largest patient organizations in the US spend more than

90% of their revenue for their own officers' salaries and for fund-raising. In the US, organizations must reveal such payments in the Internal Revenue Service yearly filing, but it is expensive to gain access to this information from the government.

If other medical groups and I would not limit this to patient organizations, observed Gary Bain's precepts, health care would be greatly improved.

Although Gary died from his COPD a number of years ago, I still remember the enthusiastic conversations we held and the good advice he gave. EFFORTS has continued operating with the good organizational principles that Gary pioneered, and EFFORTS has continued to succeed in its educational and advocacy efforts.

Acknowledgements

Disclosure: The author declares no conflict of interest.

References

1. Rommes J. Chronic obstructive pulmonary disease patient group succeeds on the internet: EFFORTS. *J Thorac Dis* 2015;7:E78.

Cite this article as: Grouse L. Gary Bain's precepts for chronic obstructive pulmonary disease patient groups. *J Thorac Dis* 2015;7(4):E79-E80. doi: 10.3978/j.issn.2072-1439.2015.04.24