Beyond the Ribbons

HIV/AIDS advocate Tim Horn highlights some golden rules for health activism.

January 3, 2018 By Tim Horn

HIV/AIDS activism is, perhaps, one of the most venerated movements in modern history—a groundswell of demonstrations and civil disobedience in the late 1980s and early 1990s that captivated the world and continues to bridge the chasm that has long separated the people from the scientists and policymakers. The lessons from HIV/AIDS activism are many—and not without controversy. But a couple of golden rules continue to shape today's activist agendas, in both the fight against HIV/AIDS and the fight against cancer.

Know the science. While HIV/AIDS activism was best known for its "die-ins" and direct actions, something else was afoot in the early years of the epidemic: Men and women, many of them living with the virus, were teaching themselves and one another the science of HIV. Not just about medical care, to better advocate for themselves and their loved ones, but also about potential targets for drug development, clinical trial methodologies and biostatistics. The result? Activists became credible in the eyes of the "experts," leading to a surge in funding, reform of Food and Drug Administration approval and early access processes and a place at high-level decision-making tables.

Scientific literacy remains a cornerstone of effective health activism. As was the case with HIV, there is an urgent need for new cancer treatments, particularly for people who don't benefit from or can't tolerate existing options. We can't push for changes in funding, health care delivery and access to treatment if we don't know what science confirms is necessary for health and survival.

Understand the barriers. The past three decades have ushered in tremendous improvements in the diagnosis, prevention and treatment of HIV and many cancers, and activism has played a major role in hastening their availability.

But availability is not the same as access, and startling disparities persist with regard to who benefits from state-of-the-art care and who does not. Just like HIV, cancer can affect anyone, but it is more likely to be diagnosed and to cause death in some groups versus others. The reasons for the disparities are complex but are frequently rooted in unequal access to care.

Scientific advances are only a win if everyone benefits. Activists must push for the research and political action needed to break down cultural and economic barriers in order to secure health care coverage for all, opportunities to participate in clinical trials of promising new therapies, access to

experienced and culturally competent providers, and an array of social services that promote health and well-being.

Activism doesn’t end when science yields a breakthrough therapy, but rather then begins the hard work of ensuring the best possible care and treatment for all. The activist to-do list includes working in partnerships and coalitions, challenging the stigmas around disease that contribute to disparities in care, and pairing meeting-room diplomacy with brash protest. Drawing on what we’ve learned from HIV/AIDS activism can help us reach the remarkably similar goals shared by health activists in the fight against HIV, cancer and beyond.

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