

WHEN IT COMES TO FIGHTING CANCER, ONE SIZE DOESN'T FIT ALL

Why disease-specific organizations are vital to research, patient support and advocacy

One of the most significant results of the online revolution of the last two decades has been the creation of information communities, organized around highly specialized topics.

The monolithic, top down, one-size-fits-all mentality that characterized organizational structures and information exchange in the mid-20th century is gone.

We're more focused and more targeted today -- connected with people who share our interests, our passions, our problems, and our concerns in ways we couldn't have imagined just a few years ago. Rather than living in one vast community, we live in countless information "neighborhoods" that are more suitable to our needs than the old way of organizing.

These communities of like-minded individuals bring many advantages – and nowhere are they more evident than in health care, where groups united by the common goal of eradicating specific diseases are much more empowered than ever before.

Just look at what disease-specific groups – such as the Kidney Cancer Association -- can do.

- Most obviously: They are focused like laser light on a single and very specific goal, which raises the chance of success.
- They coalesce the power of knowledge and create synergy because they bring together people whose experiences are very specific and very similar – whether they are health providers and researchers or patients, families and caregivers.
- They serve as a critical connecting hub – putting patients in touch with a well-organized network of experts in clinical care.
- They are often smaller in organizational size and thus can move faster and interact more intimately with their members.
- They ensure that support for specific – and often less-visible – health conditions don't get "lost in the shuffle" of research and advocacy causes.
- They are more likely to attract industry support for research and other funding needs because their goals can often be better aligned with specific industry products/services and activities.
- They create specialized and constantly updated knowledge repositories for both patients and health providers.

In light of these facts, we are troubled by the recent trend among some generalized health care groups to “take on” the specific goals and objectives of more targeted groups as a part of their ongoing operations.

We’ve seen it in other disease-specific communities, and recently we’ve noted it close to home – in the form of chronic kidney-disease charities that are beginning to include renal cell cancer (RCC) within their scope of activities.

Such trends have the potential to dilute the effectiveness of disease-specific groups like the Kidney Cancer Association, which have made enormous progress in recent years in serving the unique needs of both patients and health providers in well-defined niches.

Can a large organization focused on chronic kidney disease really serve kidney cancer patients better? We don’t think so, and if you ask kidney cancer patients, we believe you’ll hear the same answer – emphatically stated.

Just think about it: According to the National Kidney Foundation, 26 million people in the United States have chronic kidney disease, compared with just 100,000 to 200,000 kidney cancer survivors.

We believe it is obvious that a kidney cancer mission, subsumed by an organization like the National Kidney Foundation, would leave the nation’s kidney cancer survivors underserved – overwhelmed by a sea of competing priorities.

A movement from a kidney-cancer-specific organization to a kidney-disease generalist organization is like looking through a telescope from the wrong end – it’s the opposite of the concept of “focus.”

Everything becomes diluted in this scenario: The advocacy agenda becomes less targeted, the educational materials more generalized, and the patient support less specialized and personalized.

Oncologists and surgeons who specialize in kidney cancer would have little reason for participating with a larger, generalized organization that does not cater to their needs specifically, and thus the unique patient/physician network created by the Kidney Cancer Association would crumble.

Why are generalist organizations like the National Kidney Foundation moving in this direction – which is, in essence, a step backward in time? Among other things, they are competing for limited charitable dollars to fund their activities.

But that’s not going to help kidney cancer patients. Quite the opposite.

We’ve seen what can happen to consumers in the private sector when larger organizations swallow up producers of targeted or niche products and services. The result isn’t always in the best interests of individuals who have specific needs.

And we don’t see any indication that a similar trend in the not-for-profit world will have any different result.

Just a decade ago, as the Internet began to accelerate in reach and impact, a few visionary experts predicted the kind of choice-rich society we would live in as a result: A place where people find tightly focused, targeted communities of support perfectly suited for their unique needs.

It's remarkable how accurate those predictions were, and today patients are benefiting more than ever as a result.

The Kidney Cancer Association, which serves a very small slice of the overall kidney disease population, is just one example of this new environment of choice.

In the last ten years we have grown to become the nation's prime source of connection, information, and support for kidney cancer patients and their families – not by being generalists, but by focusing day and night on just one thing: kidney cancer.

That doesn't mean that we do everything on our own: Our success has largely been driven by partnerships with a wide range of other institutions – from the M .D. Anderson Cancer Center and The Cancer Genome Atlas to Cleveland Clinic, the Kidney Cancer SPORE program and Livestrong (Lance Armstrong Foundation).

Collaborative efforts with large organizations can benefit patients – but they are most likely to succeed when they are sharply targeted and well defined.

In 2011, it's all about focus. The Internet genie is out of the bottle, and it has brought us a new, better way of organizing ourselves against cancer.

Let's embrace this new world – rather than trying to go backward in time.

The patients we serve will thank us for it.

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