

# Be in the Business of Going out of Business



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**Voluntary health organizations have a unique role in connecting all the players required to get cures and treatments to patients faster.**

I make my staff nervous when I say this, but as voluntary health organizations we should be working toward putting ourselves out of a job. At my organization, The Leukemia & Lymphoma Society (LLS), we are dedicated to funding research, finding cures and ensuring access to treatments for blood cancer patients. If we are aligned around this goal, all of our efforts should go toward ending blood cancers. More simply put: we need to be putting ourselves out of business. And there is no way we could accomplish that, and deliver our mission, without engaging in collaborative efforts.

To look for a model of how this kind of collaboration can work, we simply need to look at the example

set by the National Foundation for Infantile Paralysis. In 1953, there were 120,000 new cases of polio diagnosed in the United States. One decade later, there were none. We know that in that decade the Salk vaccine was licensed. But equal in importance to the discovery of the vaccine was the distribution campaign sponsored by the National Foundation for Infantile Paralysis. With all pieces of the system working together, a disease was effectively wiped out.

The National Foundation for Infantile Paralysis is now known as the March of Dimes and has refocused its mission on improving the health of mothers and babies. Its historic work developed the model for what patient advocate groups could be

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back then, but also what they can be today. I believe we will see more organizations directly connected with and driving the key components of the work that needs to be done to see their mission succeed. Rather than remaining at arm's length from research, patient advocacy groups and voluntary health organizations will play more of a direct role. These nonprofits bring a wealth of knowledge about their specific disease area and also have a deep understanding of what patients

experience in day-to-day living.

LLS has experienced how this kind of collaboration can work today through a three-way partnership called The Learning Collaborative. With our partners, the National Center for Advancing Translational Sciences and the University of Kansas Cancer Center, we established an environment where each organization contributed its own expertise without concern for who claimed credit. It was through

a commitment from the group's leadership to adhere to a common set of goals and metrics that we found success. This experience continues to be a model for LLS when entering into partnerships. But the best practice of setting common goals and objectives can be applied to any collaborative effort regardless of the disease of interest.

Collaboration is the key to accelerating the rate that new therapies get delivered to patients. These models need to become second nature to all organizations in the biomedical research space. Voluntary health organizations can act as a centerpiece for these partnerships. We can support the researchers developing treatments, dialogue with the Food and Drug Administration on unmet patient needs, educate providers who will be delivering therapies and engage the patients who need supportive services. I am going to keep pushing my organization until I am out of a job. And I hope you will join me in that mission.

120,000



1953

0

1963

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