Helping Cancer Patients by Leveraging Social Networking

To paraphrase Shakespeare, some people are born to serve, some achieve service, and others have service thrust upon them. One day in January, 2006, Chris Ryan became one of the latter. What would move one of America’s most promising technological entrepreneurs to become a beacon of hope for those battling cancer? What would make him choose to dedicate a goodly portion of his time and wealth to creating a support network for those suffering from one of the number one killers in the world?

Ryan’s journey began with a phone call to his father shortly after the Christmas season of 2005. The holiday had not been a vacation for Ryan: he had spent most of Christmas through New Year’s hard at work. Nine months earlier he had begun a particularly complex acquisition process that was finally coming to a close. The process had been stressful, but Ryan was convinced the pay-off would be worth the time spent away from friends and family. As the project drew to a close, Ryan spoke to his father, getting him caught up on where things now stood at work.

It is the misfortune of the young to forget that things change, and often unexpectedly. The status quo only lasts forever in our minds. Ryan’s father had remained quiet and subdued throughout the conversation, and finally broke the news to his son: he was dying. The diagnosis was cancer of the liver, a particularly virulent form of the disease, and he was expected to live at most another three months.

Ryan was overcome. He was simultaneously upset, angry, and filled with feelings of helplessness. This loss of control over the situation was quickly replaced, however, with a desire to act. With all the resources at his disposal, Ryan was unwilling to accept his father’s death sentence as a fait-accompli. Marshalling all his resources, Ryan set out to do everything in his power to change what seemed to the doctors an inevitable outcome of his father’s cancer: a quick death.

His action plan was quite simple. Find the most cutting edge cancer treatment options and strategies for his father. Many people, when confronted with a disease like cancer in themselves or a loved one, approach the diagnosis in a similar way. Doctors and medical treatment facilities see hundreds, sometimes thousands of people on a monthly and
yearly basis. But a child has only one father, one mother. Who could possibly be as committed to finding the best treatment strategies and tactics as a child, or a loved one? This is no slight on the medical profession. Most doctors and caregivers readily acknowledge that the best advocates for a patient are those who love them, and they can be the best allies in the medical battle being fought inside the patient’s body.

The more Ryan researched, the more convinced he became that a cure for his father’s cancer lay somewhere other than the United States. Along with his sister, Ryan and his father traveled to an oncology clinic outside Frankfurt, Germany. This clinic specialized in an integrated treatment strategy using the best of both western medical protocols and holistic methodologies. Chemotherapy, radiation treatment, and surgery were not eschewed, but considered only one part of the healing process. The German clinic also employed harmonic and hypothermic treatments. The clinic, in concert with Ryan’s father, developed a diet and exercise regime most beneficial for helping him maintain a high quality of life. This last idea, that helping patients feel good about their lives during treatment, would stick in Ryan’s mind as a missing ingredient in modern cancer management.

While Ryan was with his father, he interacted with hundreds of cancer patients, their friends, and their family. He became close to many of them, and started to see patterns emerging in the effects cancer had on both patients and their advocates. A question arose within Ryan: shouldn’t there be some way of gathering and storing these similar experiences and sharing them with others in similar straits? Wouldn’t it be possible to develop a set of tools that would allow cancer patients and their advocates to move more quickly than he had from helplessness to helpfulness? The seeds of what would become Extensions, Inc. and the EXT network (Symbol:EXTI) and Cancer.im had been planted, and grew each day in Ryan’s mind.

Ryan’s father lost his battle with cancer on November 8, 2007, almost two years after he had received the news that he had but three months to live. In memory of his father, Ryan started an online social network dedicated to helping cancer patients and those supporting them. This new network would be based on a handful of basic goals:

1. Enable support network organization: Cancer patients need to be able to keep friends informed of their treatment process. They also need ways to organize volunteers in a fashion that encourages supporters and provides the most help to the patient.

2. Provide tools for record organization: Patients need to deal with a bewildering array of medical, financial, and legal issues, all of which come with their own records and paperwork. They need ways of keeping all this information organized and accessible, without that organizational work becoming an additional personal strain.

3. Organize facts and figures on cancer: Research into the various facets of cancer can be tedious, given the wide range of information available through the internet alone. Patients and their supporters need a single source where vetted information can be easily accessed, what is needed easily saved, and what is not useful set aside.

4. Encourage development of individual treatment strategies: Everyone being treated for cancer should be able to create an exercise plan, a diet, and a treatment plan based on his or her own values, beliefs, and resources.

An online social network that could meet all these goals, Ryan believed, would go a long way to increasing what he had learned was one of a patient’s greatest weapons: quality of life. Upon learning they have cancer, many patients fall into the same feelings of helplessness and anxiety Ryan felt when he learned of his father’s diagnosis. High anxiety is an added stress on a body that needs all the strength it has for the battle ahead. Patients with lower anxiety, Ryan believed, would not only feel better. They would also stand a better chance of beating their cancer.

Ryan developed a 15-step process that he felt would meet each of these goals. He called it a cancer MAP, or Mission Active Plan. The first step was the patient’s acceptance of the diagnosis of cancer. Although a seemingly obvious step, it is nonetheless a critical one. The succeeding steps include identifying a sponsor who has successfully battled the patient’s form of cancer, organizing his or her support network, organizing records,
researching their form of cancer, choosing an oncologist, developing an exercise and diet regime, researching medications and their possible adverse interactions with other medications a patient is taking, and preparation for treatment. The last two steps of the cancer MAP encourage the patient to become a sponsor to someone else being treated for cancer, and to share their experiences with them and others.

It was Ryan's new-found passion for helping those afflicted with cancer that brought him this far. He knew full-well that a layman’s plan would never be universally accepted unless it was validated by research. To that end, Ryan decided to take some of the wealth he had made through his technological ventures and invest it in research to back-up his intuition. Where else, then, could he go but Houston, TX, the Mecca of global cancer research? It was in Houston that Ryan met Dr. Mahesh Kanoji.

Dr. Kanoji, a native of Marmath, India, shared Ryan’s profound passion for raising cancer patients’ quality of life using both western and holistic cancer treatments. The two found in each other kindred spirits. Like Ryan, Dr. Kanoji did not have an immediate and innate attraction to cancer medicine. He had, in fact, wanted to be a cardiologist. He trained at the University of Bombay, India and came to the United States in 1976 for a research fellowship. After spending time with people being treated for cancer, Dr. Kinoji changed course and decided to pursue advanced training in oncology. He completed a fellowship in hematology at the University of Georgia, followed by a medical oncology fellowship at the University of Texas’ MD Anderson Hospital in Houston, before joining the MD Anderson faculty. There he pursued research into bone marrow transplantation and advanced gastro-intestinal chemotherapy for the treatment of cancer. Dr. Kinoji moved to Beaumont, TX in 1983. There he founded the Julie and Ben Rogers Cancer Institute and the Beaumont Cancer Institute, and continues to serve as the latter’s Medical Director and President.

Like Ryan, Dr. Kanoji was convinced that the treatment of cancer was more than just dosing with chemicals, radiation therapy, and cutting out tumors. He was convinced there was a role for nutrition, exercise, and mind-body harmony in cancer care. He began developing a western protocol / holistic medicine combination therapy. Convinced from a reading of the history of medicine that herbal medicines were of value, he began to study and integrate traditional Indian and Chinese medicine with his western cancer treatments. He traveled extensively, observing the art of ancient medical traditions. In 2003 Dr. Kanoji founded his flagship Wellness Center in Houston. There are now several branches of this initial center, operating under the name Integrated Wellness Centers of America, Inc. (IWCA).

Chris Ryan and Dr. Kanoji eventually integrated their ideas to form what they would call the Kanoji Cancer Protocol. Many aspects of this protocol have already been validated by research. Clinical studies have shown that an increased quality of life correlates with a lower morbidity rate in cancer patients. Studies have also demonstrated that patients with a strong network of supporters battle their cancer more effectively than those who try and do it on their own.

Meanwhile, Ryan was hard at work developing the software tools and information technology infrastructure that would make implementation of his MAP process a real possibility. First, there would need to be a social networking site that would allow members to be both public but would also allow private 'micro' social networks (MSNs). Members would need to be able to create profiles pages that would be public, and others that would contain private information available only to their closest friends and family. A public profile could serve the same function as a listing in the phone book, while a private profile could contain intimate information about treatment progress, therapy appointments, requests for help and prayers of support.

This new network would also have to have research and knowledge capturing tools integrated into its platform. The volume of research data on the numerous types of cancer, treatment methods, drugs, effects of exercise, new forms of diet, and other aspects of cancer treatment continues to increase every day. A robust database of searchable, vetted information had to be a part of this new network.

Methods of capturing the wisdom of cancer patients would also needed. The approach taken was to develop a set of interview questions that could be asked of all cancer patients willing to share their experiences. Their answers to these questions could be captured on video, and each video clip indexed by the type of cancer, demographics of the
patient, and keywords contained in their answer. This video knowledge-capturing approach would come to be known as VIEW, standing for video indexed encapsulated wisdom.

What began to take shape as all these tools were developed and put together was the EXT social network. The network took its name from the ‘experience transfer’ component Ryan believed would be an essential part of his cancer social network. What started out as a vision of creating a social networking tool for cancer patients, survivors, advocated and organizations became, along the way, the next generation social-networking site.

In 2007 Extensions, Inc., the company behind both EXT and what would become the Cancer.im social network went public and began trading under the public symbol EXTI. By 2009, the company had rolled out both its EXT social network and its Cancer.im site.

From the moment Chris heard of his father’s diagnosis, he was committed to improving the lives of other cancer patients. His single-minded desire has been to improve the quality of life of other victims of cancer, using the research that helped his own father in his battle with the disease. Ryan sees his work on EXT and Cancer.im as a tribute to his father. Every person he helps is validation that his father’s death was not in vain. Even if cancer closed the door on his life, it will hopefully through the work of his son open the door of hope to thousands of others.

Cancer.im’s mission statement tells in simple terms what this network is all about and hopes to accomplish. This new network, the dream of a man who lost his father to cancer, seeks first of all to “empower every cancer patient with the information and resources they need to create a customized cancer strategy.” Cancer.im exists to help those dealing with the disease conquer their feelings of helplessness and hopelessness by returning to them control over their treatment. The network will help others who have fought cancer and survived share their wisdom and experiences with others. It will empower a cancer patient’s support network, and lastly, provide the tools necessary for them to proactively maintain a high quality of life.

This website, with the potential to benefit so many, came about through the time and effort of just one man. Even Ryan is amazed to see his dream come to fruition. People are already benefiting from the database of information available, over 62,000 items and growing continually. Patients are communicating and organizing their supporters. Friends and family who didn’t know what to do or say now know how they can help.

With Cancer.im Chris Ryan planted a seed, a seed of hope. From that seed has blossomed a wellspring of support, information, knowledge, and wisdom. Ryan is convinced there is no limit to how far reaching the impact of Cancer.im will be for the people who will utilize this network. Ryan’s dream of changing the way cancer patients view and manage their disease is now becoming reality and, with continued support, the possibilities are limitless. From Ryan’s loss of his father, thousands and perhaps millions can now find hope.