USING SOCIAL MEDIA TO SAVE LIVES: HELPVINAYANDSAMEER.ORG

Team Vinay and Team Sameer were two start-ups coming together. The volume of things that we had to get done around recruiting, building a brand, and building awareness, were very consistent with the activities of a start-up company. We needed commitment from everyone involved, had to stay focused on clear goals, and needed performance metrics.

—Robert Chatwani, head of Team Sameer

Sameer Bhatia was a 31-year-old South Asian American Silicon Valley entrepreneur who had started a company called MonkeyBin in 2000, the first online community and consumer marketplace for barter or trade, and then a mobile gaming company, Octane Technologies several years later. When visiting Mumbai, India in May 2007 with his wife of barely a year, he started to feel under the weather. He wanted to blame the nausea, lack of appetite, and racing heart beat on the humid 100-degree monsoon weather, but in his heart, he knew something else was wrong. He went into the doctor and heart tests revealed a possible atrial abnormality. The doctor ordered blood tests which revealed a bigger problem—a diagnosis of Acute Myelogenous Leukemia (AML). Sameer recalled: “I looked at him [the hematologist] like he was crazy. I had researched a dozen different infectious diseases, a couple of which matched my symptoms identically. But he noted the strong presence of blast cells in my blood and said there was a 99 percent chance that this was leukemia. He wanted to admit me in the hospital immediately.”

1 The company’s assets were sold in 2003.
2 Immature blood-forming cells found in bone marrow but not found in healthy blood streams.
3 www.helpsameer.org.
By 1:45 a.m. that night, Sameer and his wife Reena were on a flight from Mumbai to Newark, New Jersey, having managed to get the last two seats on a flight.

**ACUTE MYELOGENOUS LEUKEMIA (AML) AND TREATMENT**

AML is a fast-growing cancer of the blood and bone marrow (bone marrow produces the body’s white and red blood cells and platelets) ([Exhibit 1](#)). Of the four types of leukemia, survival rates for AML are the lowest at 21 percent, although some reports state survival rates of up to 50 percent, depending on individual patient factors.¹

Treatment plans for patients with AML can involve chemotherapy first and sometimes radiation to destroy the diseased marrow, followed by a bone marrow transplant to replace the destroyed marrow. Finding bone marrow is not an easy task, however. The bone marrow donor’s tissue type needs to match the patient’s type as closely as possible (a 10 out of 10 match of certain parameters is ideal). But 70 percent of leukemia and lymphoma patients do not find a genetic match in their families and thus depend on nonprofit organizations like the National Marrow Donor Program (NMDP), an American nonprofit which maintains a database of registered donors, to help them find an unrelated donor or cord blood unit.⁵

After several rounds of unsuccessful chemotherapy and radiation, the doctors told Sameer that he needed a bone marrow transplant. At the time, there were 6.5 million people registered in the NMDP. However, only 1.4% were of South Asian descent.⁶ Since tissue types are inherited, patients are more likely to match someone from their own ethnicity. Thus, whereas a Caucasian had a 1 in 15 chance of finding a donor match, South Asians had only a 1 in 20,000 chance of finding a match. More problematic was the fact that only 30 percent of South Asians identified as a possible match went in for follow-up testing (lowered retention rate).⁷ For other ethnic groups, the follow-up testing rate was between 70-80 percent, and for other Asians, 30-40 percent.⁸ To make matters worse, Sameer had an unusual gene on his father’s side of the family. And in India, a country with more than one billion people, there is no bone marrow registry.

Ultimately, Sameer did not find the match that he needed. Thus Sameer’s friends and family decided to take matters into their own hands. But they had to move quickly; they only had a matter of weeks to register as many people as they could into the donor database.

**THE BIRTHS OF TEAM VINAY AND TEAM SAMEER**

In November of 2006, another young South Asian American professional, Boston-based Vinay Chakravarthy, a 28-year-old physician had also been recently diagnosed with AML. Vinay was also newly married for a little over a year, to a woman named Rashmi.

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⁴ Retention rate was just for follow-up testing, not for actual donating.
When Vinay was first diagnosed, his friends, family, and community, led by Priti Radhakrishnan, Vinay’s childhood best friend who was a lawyer and a patient’s rights advocate, wanted to start a campaign to enlist South Asian Americans to register with the NMDP. “I had a close friend who was diagnosed with AML in 2000 and who passed away in 2001.” Radhakrishnan explained. “We organized bone marrow drives for her, but we were too late. When Vinay relapsed in May 2007, his family and Radhakrishnan launched “Team Vinay” with the goal to register 20,000 people of South Asian descent as fast as possible.

A few weeks after the launch of Team Vinay, Robert Chatwani, one of Sameer’s best friends and co-founder of MonkeyBin, mobilized Sameer’s friends and launched “Team Sameer.” One of Sameer’s college friends, Sundeep Ahuja, was also a member of Team Vinay. Thus, Ahuja and Radhakrishnan immediately scheduled a conference call with the two teams to discuss how they would work together. “It could have been more complicated than it was. Team Sameer recognized early on that the smartest thing to do would be tap into our team’s efforts and work in concert. So their communication started to feed into ours, and they began going to our bone marrow drives to help strengthen them. We essentially became one big campaign,” said Radhakrishnan.

Getting involved with such a campaign was not an easy decision for Sameer, who reflected in his blog how Robert was not only instrumental in the bone marrow registry campaign, but in getting him to go public: “When my best friend, Robert, first approached me with the idea of ‘going public’ to mobilize South Asians from around the country to register as bone marrow donors, I was hesitant, particularly as an entrepreneur running a business at a crucial inflection point. But Robert persisted and put my worries to rest, more or less saying, ‘Just let us use your name and we’ll take care of the rest.’”

Eventually, Chatwani convinced Sameer to go public, as long as the team did not use Sameer’s last name or mention the company’s name.

**DEVELOPING A FRAMEWORK, EXECUTING ON A STRATEGY**

The challenges facing Team Vinay and Team Sameer were daunting. “We all knew we needed to do something. And we realized our choices were between doing something, anything, and doing something seismic,” explained Chatwani. “When framed in this way, the answer became simple: If the odds were 1 in 20,000, all we needed to do was hold bone marrow drives and register 20,000 South Asians. The problem was that we had a matter of weeks to actually get this done. We needed to (a) focus sharply, (b) immediately grab people’s attention, (c) engage them and (d) inspire them take action.”

Staying focused meant having a single clear, measureable goal: getting 20,000 East Asian individuals into the donor registry immediately. Grabbing attention meant making the message bold, crisp, and human, and using many channels. One way of grabbing attention was to “have a clear goal,” according to Chatwani. “Keeping things simple helped everyone really understand what we were focused on.” Engaging meant funneling traffic to a single destination and being personally meaningful. Finally, taking action meant making sure all communication had a clear call to action and tracking metrics and collective impact.

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Teams Vinay and Sameer put together a two-pronged strategy at a macro level to achieve their goals (Exhibit 2). First, they wanted to build an instant brand by quickly generating awareness of their efforts through social media and traditional media. Social media included blogs, video, viral e-mail, Facebook, widgets, pledge lists, etc. Traditional media included public relations, television, magazine, telemarketing, posters, and newspapers (discussed below in further detail) (Exhibit 3).

Second, they wanted to develop a mass micro-mobilization strategy to drive action amongst as many South Asians as possible, through education, with the goal of getting people to register. Micro-mobilization involves the participation of individuals in a movement, often using Web 2.0 media. Education entailed how-to videos, web links, donor organizations, and social media technologies (e.g., Facebook). Chatwani said: “Because being a part of the bone marrow registry sounded scary and potentially painful, education was a huge part of our focus. We wanted to make sure people knew registering was quick and easy, just a cheek swab that takes minutes.”

(Exhibit 4). So as to make registering easy, they held bone marrow drives where individuals were living or working—corporations, homes, universities, temples, and clubs/lounges.

Although the teams had developed structures, strategies, and processes, in reality, they were moving at breakneck speed. Sundeep Ahuja elaborated: “It was like the perfect storm. We believed in ‘act first, then think.’ The people that were acting had experience though, and knew enough to make the right decisions on the fly so that everything would move forward. There was some trial and error, but with such a compressed time frame, it would have been hard to let all the errors play out and learn from those mistakes.” Ahuja added: “For example, once we saw that workplace drives were working, we didn’t think of much else. We put some banners on our site and noticed that they weren’t driving registrations, which was our clear goal, so we let it go. Our motto was abandon, move on, abandon, move on, move on, etc.” Chatwani added: “We often tried to think of the traditional way to do something and considered what would happen if we did the exact opposite. We weren’t wedded to a right way of moving ahead. We just moved ahead. And we empowered others to move ahead just as quickly.”

**WHAT DID THE TEAMS DO?**

Both teams moved quickly after launching. Chatwani explained, “Both of our teams ran at 1,000 miles per hour. We went against the idea of moving forward with a thorough plan. If you don’t try it, you’ll never know if it was right or not.” He added: “However, looking back on it, it

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12 Registering with the NMDP involves a safe, simple, and non-invasive 15-second procedure where a sample of cells from the inside of the cheek is taken with a cotton swab for tissue typing. Potential donors sometimes pay a fee (around $50, which is sometimes reimbursed) for the tissue typing and could reserve the right to change their minds at a later time if they are identified as a match for a potential patient. There are two ways to harvest blood forming stem cells in bone marrow. In the past, donation involved minor surgery to draw marrow from the hipbones. Today, the most common way of collecting the stem cells is by filtering them directly from your blood. Although deemed safe, potential donors often fear that the procedure of registering and donating will be invasive, but according to NMDP, both registering and donating involve little risk.
seems as if we ended up following a five-step process: 1) Get organized and form teams, 2) Build the “brands”, 3) Create the architecture, 4) Recruit volunteers, and 5) Execute like crazy.”

**Getting Organized and Forming Teams**

Team Vinay organized first, with an informal decentralized structure defined by two sub-teams—one focused on donor drives and the other on strategy and communications, for a total of 15 people. The drives team focused on setting up drives to recruit registrants. It had national coordinators and different state leaders. The drives team also coordinated with local organizations, churches, and other venues to host the drives.

The communications and strategy team focused on awareness and action—publicizing the drives, driving people to the website, and crafting messages to motivate the community toward action. Radhakrishnan emphasized: “It wasn’t as formal as it sounds. From the beginning, it was clear who would be good at what. Family and friends just started doing the drives, publicizing and educating. They started organically from the ground up locally, and their efforts spread to other states.” She added: “A lot of public health campaigns that I have worked on tend to be top-down, even when they don’t mean to be. One of the state coordinators, Seema Patel, gave us helpful early advice, which was, ‘Don’t think of yourselves as leaders of what’s about to happen; think of yourselves as the nerve center. Your main job is to be responsive and inspire other people to become leaders. And when people become inspired to become leaders, they are going to need tools, resources, education, and support, so that’s your role—as supporters, not leaders.’ That’s the model we operated with because we had to attend to Vinay’s medical needs.” Ahuja added: “We wanted to focus on ‘empowerment marketing’—empowering people who received our message to take action.”

Team Sameer organized slightly differently, according to Dayal Gaitonde, another one of Sameer’s closest friends who was a key member of Team Sameer. The core team consisted of about 10 people who worked on different areas. “Team Vinay had two parts to their team, but it didn’t make sense for Team Sameer to be organized that way. We structured our team according to what we needed to get done or by role—marketing, technology, operations, education, drive support and had a team lead for each.” The technology team focused on the website, blog, and other social media. Team Sameer member Nick Meyers established the website and the blog. Gaitonde focused on the social media portion of technology. Gaitonde’s wife, Meeta, focused on organizing drives. There were also regional leads focused on drives in different geographic areas around the country. Chatwani focused on marketing.

**Built the Brands**

Both teams used business nomenclature (e.g., “brand”) because many of the core team members had business and entrepreneurial backgrounds. Ahuja elaborated: “We operated very much like a start-up company. We developed strategies, objectives, and talked about execution.”

**Websites**

The websites, www.helpsameer.org and www.helpvinay.org, were the main mechanisms to build the two brands *(Exhibits 5 and 6)*. The teams also developed another collaborative combination
site called www.helpsameerandvinay.org. Both teams set up their websites within a matter of days after launching their teams. Each of the websites included photos of Sameer, Vinay, and their family and friends, biographies, upcoming donation drives, frequently asked questions about donating, videos, news, and blogs that documented Sameer and Vinay’s daily successes and struggles. “We wanted to develop a sense of community and a central place where there could be blog posts, communication, and interaction,” Chatwani said. “These sites became our home base, a central place that people could keep coming back to for updates and new information.” Gaitonde added: “It was important to tell Sameer’s story well. People get much more engaged when website is personalized and feel that they need to take more action. So it made sense for us to form our own website independently.”

Despite independent sites, the two campaigns made the conscious decision only to list donor drives on Vinay’s website. Chatwani explained: “Vinay’s site already had an infrastructure set up. When it came to drives, we didn’t want to have two places for people to go for information. We wanted all information in one place. Whenever we had new drives hosted by family and friends or volunteers, we would report date and location details back to a specific individual on Team Vinay campaign. We would then point to that information from the Sameer site.”

**Email**

One of the first things Team Sameer did was craft an e-mail message to spread the word quickly (Exhibit 7). “We wanted to get the wheels in motion,” said Chatwani. “What better way than to just send an e-mail? The e-mail was specific and action-oriented around informing people about the situation, telling them what they could do, and asking them to spread the message even further.” Chatwani spent “hours and hours and hours” trying to craft the perfect three-paragraph e-mail, which he sent to nearly 400 people with a call to action to send the message on to someone else. Chatwani then sent the e-mail to employees at eBay, Inc. where he was employed, and a friend at Oracle sent it out to their distribution list and to other South Asian networks. Chatwani estimated that within 48 hours, 30,000 to 50,000 people received the e-mail message. The rapid influx of inbound e-mails led Chatwani to focus on getting structured by forming a team and putting some communication tools in place.

**Messaging**

Targeted messaging was critical in building the right brands and reaching certain populations to enlist registrants. Further the messages relied heavily on photos to grab people’s attention, and make Sameer and Vinay feel more “knowable.” Chatwani elaborated: “In some messages, we focused on their South Asian background. In others, we highlighted their young age or their newlywed status to resonate with people in their twenties or thirties. We also focused on their professional pursuits, how Sameer was a technology entrepreneur and Vinay was a doctor. We wanted our audience to be able to see themselves in Sameer and Vinay.”

Early on, the teams decided not to create messages asking for money. Radhakrishnan said: “A lot of the key decisions were made by Vinay himself; he was guiding the messaging. The South Asian community is wealthy and a lot of people wanted to donate money. Vinay felt that by accepting money, you were telling people that it was okay not to go and register. We were really focused on what our angle was, our goal, and money wouldn’t have gotten us there.”
Team Vinay also wanted to make sure that the messaging about donors was clear. Radhakrishnan explained: “Vinay knew early on that a lot of people were registering for him and if they received a call for someone else, they might not do it. So Sundeep and the communications team were clear from the beginning that any effort to start a drive, get someone to register, raise awareness, etc. had to reinforce the messaging that if you’re going to be a donor, be a committed donor—which means that no matter who the call is for, you’ll come in.”

**Blogging**

An important brand-building force was blogging by both Sameer and Vinay. Sameer was a prolific, passionate, and spirited blogger. Ahuja said: “The foremost driver of success was each of their stories and how they communicated those stories via their blogs.” Chatwani added: “Initially it took some convincing to get Sameer to blog, but when he started to write, his personal story truly emerged. It was a whole new sort of thrust to the campaign, because people could hear his voice. That was powerful.”

Vinay and Sameer had different blogging styles. Chatwani said: “Sameer was open and said, ‘Put me out there, talk about me, tell me what you need me to do.’ Vinay was more reserved, but his story was still very human.” In fact, Team Vinay had consciously created Vinay’s brand to be a sort of “every-man” brand, according to Radhakrishnan: “I think Vinay’s personality was laid back, partly, but it was partly a strategic decision for him to be a regular dude so everyone who read his blog could identify with him…. With Sameer, he was so charismatic that when he would walk into a room, everyone would turn and look. He was sharp, funny, smooth-talking, so that’s how we built the two brands.” Ahuja elaborated: “I think Vinay was very chill, but it was this quality that helped him to relate to people.”

Sameer constantly maintained a positive attitude despite his setbacks. While waiting for a bone marrow match at his Mercer Island home near Seattle, Sameer wrote: “As my friend, Veer, points out to me: how often is it that, in your 30s, you get to spend an entire summer with your parents?!“ And even with leukemia, Sameer seemed never to slow down: “My days have been absolutely packed with daily visits to the SCCA (Seattle Cancer Care Alliance) clinic and bi-weekly blood and platelet transfusions. On top of that, I have been working full-time to close a couple of monumental deals for our business (one down, one to go!).”

While Vinay was waiting for his transplant, he tried to keep busy. He blogged: “As for me, things are going well. I only have to go in for check-ups once in 10 days instead of the 2 to 3 times a week. My counts are looking good and every day I seem to get more of my energy back. I take walks when the weather permits…. I did take a little jog the other day to test my stamina…. I am really out of shape. After a short jog, I was huffing and puffing and it took me a while to catch my breath. But I have to say that it felt good to get the blood flowing. Rashmi bought me some dumbbells and I have slowly started some light weightlifting (trust me, they are truly light weight). I spend most of my days watching a lot of sports on TV. Recently, I have gotten bored with television so am trying to make myself more useful around the apartment and I

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finally finished reading the Lance Armstrong book for the second time, now I am starting to read the *Kite Runner.*"\(^{15}\)

Both teams expressed their frustrations with their community’s apathy towards registering and donating on their blogs. Vinay’s wife, Rashmi Rao (on Vinay’s blog), said: “We are part of a community that will use all the resources without questioning any of it. But when asked to donate to the same pool, we seem to be the most hesitant. It doesn’t seem right, does it?”\(^{16}\) Sameer wrote on his blog: “South Asians who have taken the trouble to register as donors only step up 30 to 40 percent of the time called upon as a match. I hope we can all reflect on that number for a second and realize how despicable it is…. Our enemy here is part fear, part ignorance, and partly this remnant survivalist desi [a colloquial name for people of South Asian descent] instinct where us Indians will only help our own flesh and blood.”\(^{17}\)

Both Sameer and Vinay made pleas to their readers to overcome their fears of both registering and donating. For example, Sameer said: “Can you ever imagine the fear that most cancer patients must experience? You begin to realize the meaning of living life one day at a time. You understand that nothing is certain, not even the sun coming up tomorrow. You realize (if you are spiritual) that god is the only constant, the only certainty. If you can successfully come to all of these realizations, you can maybe eliminate most of your fears as a cancer patient. As a donor, hopefully the path to being free of fear is a simpler one. Please think about this, discuss it with South Asians you know, and spread the word that life’s too short to live in fear—especially when you could instead live as a hero who saved a life! Tell them that I’m the patient and I’m not afraid—are you?”\(^{18}\)

**Created the Architecture**

When the teams started their campaigns, they had significant tasks ahead of them. Initially, they realized their progress needed to be “exponential,” as Chatwani explained: “We knew that each day there were billions of Google searches, text messages, and instant messages being sent throughout the world each day. We needed to achieve exponential visibility and these technologies enabled us to do exactly that. Our ultimate goal was to mobilize action offline.” Chatwani discussed the challenges of marrying an online and an offline campaign: “We first had to mobilize people online to actually show up at a physical drive—and time it such that we could alert them to a drive location in their local area. Our teams were coordinating this at a national level so getting these two activities synchronized was tricky. But the strategy worked, particularly since there were so many volunteers across the country who were hosting and managing the donor drives.”

To enable the strategy, the team harnessed social media including Facebook, Twitter, Myspace, Google Docs, Google Groups, YouTube, and infoUSA.com. Gaitonde explained: “We defined social media as anything that allowed us to share information amongst people in our networks, or possibly even those we don’t know, using Internet and mobile-based tools. With the

advancement of so many social media tools, there is really no limit on the number of people you can reach or the amount of information you can put out there. Also, the audience can participate and interact with one another. It’s open communication where the interactions themselves can take on a meaning of their own.”

For internal team organization and communication, Team Sameer and Team Vinay used Yahoo! and Google Groups, conference calls, e-mail distribution lists, and phone trees. Organization was aided by Google Docs, which is a set of free, web-based word processor, spreadsheet, presentation, and applications tool that allows users to create and edit documents online while collaborating in real-time with other users. For example, Team Sameer used Google Docs to organize a telemarketing campaign to a list of people with the last name Bhatia. Ahuja explained: “We just dumped a bunch of names in there, divided them up, and asked people to call them.” With Google Groups, Team Sameer started “The Samba Lounge” (Samba was Sameer’s nickname) where friends and family could connect and support each other, as well as get and give updates on Sameer’s health.

For the potential registrants, the websites were the central places to get and share information. The teams used the “Tell a Friend” feature, a marrow drive location list and calendar, useful links, donor videos, pledge commitment lists, and FAQs. ”The websites were the central places where people could interface with Sameer and Vinay, and each other. On Vinay’s site, we had an “I Registered” campaign where registrants entered their names. That was huge because you could see your friends’ names up there when you visited. We made an effort to try and have the call to action abundantly clear. The text on the sites read: ‘Hey visitor, have you already registered? Click here to get others to register. Have you not registered? Click here to find a donor drive in your area to register.’ The online calendar that listed donor drives by state was critical as another call to action,” said Ahuja. Asia Blume at the Asian American Donor Program added: “This was the very first campaign that I had seen harness social networks the way it did and use them to their potential.”

**Recruited Volunteers: Empowerment Marketing and an “Open Source” Campaign**

When Vinay learned that his intensive chemotherapy was not effective and that he required a bone marrow transplant, his team posted ideas on his blog suggesting ways in which volunteers and readers could help—organizing drives, registering, and getting others to register. Each suggestion included detailed guides and information to help people get involved. One of the first empowerment marketing tools they created was a how-to dummies guide called “Hosting a bone marrow drive at work,” a word document with simple instructions and sample e-mails that could be customized by others as needed ([Exhibit 8](#)). Further, the teams provided a link to downloadable PDFs of the family’s appeal, a Tell-a-Friend link that led to Vinay’s website, e-mail templates that people could send to their friends, footer templates that people could add to their e-mail signatures, banners to put on blogs or websites, and a Help Vinay video that people could add to their own Facebook page.19 Chatwani said: “Within a matter of weeks, we had bone marrow drives at 15 to 20 Bay Area companies including Cisco, Intel, Oracle, eBay, PayPal, Yahoo, Genentech. Volunteers on the East Coast started using the document as well.”

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The two teams labeled their efforts to get others to help, “Empowerment Marketing.” In fact, Chatwani attributed the turning point of the campaign to their empowerment marketing efforts. “We knew we were doing something right when people we didn’t even know started to self-organize, and the campaign began to grow faster than we, as organizers, could architect the growth—just like with a great company. When you have others leading and contributing to your growth in a significant way, to the point where you don’t even know of most of the activities that are going on, that’s powerful.” Chatwani continued: “A contributing factor to the success of Team Vinay and Team Sameer was the fact that people felt the call to action to pick up and carry out on their own. They weren’t dependent, necessarily, on someone from the campaign briefing them about what was happening. We built a campaign that others could build upon. A true sign of an open platform is that no one should have to ask you permission to contribute. They should be empowered to connect to the cause and run with it entirely on their own.”

Radhakrishnan originally recruited Ahuja to work on empowerment marketing for Team Vinay, a strategy he executed while running marketing for the non-profit Kiva.org. Ahuja described his initial thinking: “We have this community, how do we now let these people do something for us? We were decentralized and didn’t have any money, but there were people that wanted to help. So the idea was to tell them how they could help. We made a wish list such as needing celebrities or banner ads, etc. And we publicized this and asked people to just take it and run with it.” Like Chatwani, Radhakrishnan felt that empowerment marketing was essential: “We had so much to deal with. We were probably getting thousands of e-mails from people because of the early television and media coverage we got. We quickly realized that there was no way that we were going to answer all of those e-mails.”

The premise of the teams’ empowerment marketing philosophy stemmed from a seminal article, called The Architecture of Participation, written by author Tim O’Reilly in 2004. According to Chatwani, the article was a cornerstone of inspiration for the world of Web 2.0. O’Reilly believed that there are systems that are created for people to contribute content, ideas, and knowledge and when you begin to connect these systems, you can begin an interaction and development of ideas. Chatwani added: “With open source software, there is a standard platform, but you need many people to contribute to its progress, which is more powerful than any one company developing on the platform itself. You just need to ensure you provide the hooks to connect to the architecture in the right way. That was also true of our campaigns. Our websites were ways people could connect into our campaign. Individuals could go there and learn how to host drives, spread the word, get registered, volunteer, etc.” The team created a four-winged model (reminiscent of a dragonfly), which provided links to useful websites that allowed anyone interested in helping download critical information (Exhibit 9).

Another example of empowerment marketing was the appearance of online banners on the Internet (Exhibit 10). Chatwani said: “We don’t even know who made many of the marketing banners. They just appeared one day.” He added: “The power of a good campaign is that others will do things that you don’t expect. All of a sudden these banners were being published on various sites. People could download them and put them on their blogs and drive traffic back to Sameer and Vinay’s sites for awareness and action.”
Others created videos for YouTube (Exhibit 11). “We had no idea who created many of these powerful videos but every week we would see new collateral emerge,” said Chatwani. “It was amazing because it would just continue to add to the power of the campaign and extend the reach of our efforts.” Beyond drives, banners, and videos, other blogs also picked up Sameer and Vinay’s stories. Sameer was featured on Valleywag [a news and gossip blog about Silicon Valley personalities], which drove significant traffic to his website (Exhibit 12).

On their own websites, the teams had a thermometer that listed the goal and weekly progress towards the goal of 20,000 registrants. Chatwani said: “We were transparent, which helped to engage and motivate people. When the campaigns were hitting the registration goal numbers everyone knew we were succeeding. But people would know when we were failing. But this only inspired volunteers to do more and try harder. The transparency and clarity was empowering.”

**Executed Like Crazy**

The teams tried everything and constantly brainstormed new ideas. They “left no stone unturned,” according to Chatwani. One example discussed above was Ahuja’s idea to call people with the name Bhatia. Team Sameer contacted infoUSA, a mailing list service, and purchased a list with 1,391 names of people called Bhatia for $150, which was the only cost of the entire campaign. Of the available names, 689 had listed phone numbers. Volunteers started a telemarketing campaign to encourage people to register.

Part of “executing like crazy” meant demonstrating persistence. Chatwani said: “Like any good entrepreneur starting a company will tell you, you are going to need help, and you can go and ask people for help, but they’ll say ‘no’ and reject you. But another way to approach people is to say, ‘Here’s what I need from you.’ It’s a subtle shift in mindset and approach. When you ask, you open yourself up to rejection. If you tell someone what you need, you’re really not giving them an option. They may try to say ‘no,’ but if you’re persistent enough, they’ll respond.” Chatwani cited the Vinay campaign and the acquisition of a letter from Senator [at the time] Barack Obama in July 2007 as an example of seeking a prominent endorsement to lend horsepower to the campaign (Exhibit 13). “We got strategic advice from people who were active in politics and reviewed our introductory letter to Obama for us.” As a result of the advice, they sent the letter from Radhakrishnan versus Vinay himself. “That was a tactical decision because campaigns are generally reluctant to endorse just one patient,” noted Radhakrishnan. “Our letter was framed so that it was from the community. By supporting Vinay, Obama would be supporting a community and also have a broader public health impact.” The July 2007 letter from Obama said: “Vinay Chakaravarthy is a son, a husband, and an aspiring doctor...[together], we can save his life.”

**The Results**

After 12 weeks of focused efforts that included 480 bone marrow drives, 24,611 new people had registered. The teams had recruited 3,500 volunteers, achieved 1 million plus media impressions, and garnered 150,000 visitors to both sites. Blume from the Asian American Donor

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Program, said: “This is the biggest campaign I’ve ever been involved with. Other patients might register maybe a thousand donors. We never imagined that this campaign would blow up to this extent.”

Vinay found a match first, in August 2007. It was a 9 of 10 match from a donor who checked off the ‘Southeast Asian’ donor box. Two weeks later, Sameer found the rare 10 of 10 match from a South Asian donor. Chatwani said: “When we were doing these drives initially, Asia told us that if Sameer and Vinay found matches, most likely the matches would not come from our activities but that our work was still important because it would benefit future patients.” But Blume added: “We are pretty sure that both Vinay and Sameer’s donors came from the campaign efforts, based on the timing of when the donors came into the database.”

When Vinay found a match, he wrote: “Today is the Day!!! This is the day my new life begins!! I went through six days of chemo and radiation therapy and there were definitely some ups and downs, but I’ve really only had one tough day. It was after my sixth radiation treatment…. I am back to the room and could barely sit up in bed. I slept the whole day and would get angry and grumpy when people tried to wake me in order to take my pills. I’ve never known fatigue like that and although I’m sure to have many more days like that (or maybe worse). I’m so thrilled and excited to be able to go through the transplant today.”

When Sameer found out about his match, he blogged: “First, let’s look at the numbers: 1 out of 20,000 South Asians finds a match. If those odds weren’t tough enough, my search team at the Hutch found that I have an unusual gene on my father’s side of the family, which would prove to be extremely difficult to match (in fact, we went the extra mile to type all of my cousins on that side of the family, and the closest we got was a 2/6 match). To boot, it would take 4 to 6 weeks for any new registrant from a drive to show up in the national database, and I would need many more than 20,000 new registrants to have a statistical chance at a match. Bottom line: finding a match through this process in the time required would be nearly impossible. Yet many hundreds of hands and hearts around the nation united behind this cause…. You all have given me a new lease on life and for that I don’t have adequate words to thank you.”

**Follow-Up**

Sameer’s transplant was completed in the fall of 2007. During his pre-transplant preparation, the treatment team opted for chemotherapy and total body irradiation (TBI) for the pre-transplant process during which his immune system was essentially “wiped out” to be replaced by the transplanted system. One day before getting his transplant, or one day before being “born again” with a new immune system, Sameer exhibited optimism and a sense of humor: “I consider myself to be extremely lucky. I’ve had near normal energy levels and no pain or discomfort…. Until then, we are enjoying the hospital food, trying to return phone calls from friends, and continuing to get some work done. Oh, and in case you were wondering, the reason cancer patients are bald is to maximize their Kissable Surface Area (KSA)! Isn’t that obvious??”

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One of the innovative things that Sameer did was to post pictures and video of his bone marrow transplant on YouTube (Exhibit 14). In a blog entry on the day of his transplant, he wrote: “My new bag-o-cells finally cleared baggage claim, customs, passed by duty free without spending too much money, cleared the laboratory, and arrived tired but looking fresh at 2 a.m. last night. Patti, an 18-year veteran Hutch nurse, checked the precious bag, hung it (without tearing it!), and then let the new stem cells slide right into me through my Hickman line. It was simply magical.”

The videos consisted of small clips of different parts of the procedure, with the first clip showing Sameer anxiously looking at the bag of bone marrow and touching it while looking for his name on the bag. Someone in the background told Sameer not to move it around too much, to which he laughed and responded: “Don’t move it around too much? It made it through baggage claim!” Another clip showed Sameer holding the tube connected to his body and watching pensively as the bone marrow cells made their way into his body.

Despite all of Sameer’s medical team’s efforts, he relapsed within three months of his transplant. Kumar wrote on December 21, 2007: “We have had a setback in the last few days. On Friday night, we had a call from the clinic. The doctor said that they had observed blast cells in the blood test which is indicative of a relapse.” In typical Sameer fashion, he was back to blogging on December 26, 2007: “I don’t believe in setbacks. Forward is the direction we must go. As Swami Vivekanandanda famously said, growth is life and contraction is death. We must grow from this experience, whatever pains—physical and emotional—it brings us. What else, after all, is the process of life if not growth? I had my most depressing days after the suspicion of relapse first hit. And they were really down days….. The team surprisingly told me that I could call it quits now and just run away from chemo and doctors if I wanted. I looked at them like they were crazy!”

Kumar continued to give updates when Sameer himself couldn’t—he developed a fever on December 30, 2007 and other problems that required him to return to the hospital quickly. Sameer appeared in his blog between Kumar’s posts when he was feeling better. On January 15, 2008, he enthusiastically blogged: “10 days ago, my bone marrow showed 19 percent blast cells. Things were looking rough…. Today, my bone marrow showed 2.3 percent blasts!! What the …? There was no chemo in the interim…. But I am back in remission!! What I must explain about this is that this was a very unlikely and improbable result…. Now I just need to get out of this hospital and get active again. I’ve become a bit weaker…but certainly not mentally!!! 

But despite the improbable results, on January 24th, a biopsy showed 31 percent blast cells in Sameer’s marrow, showing that the prior test was probably inaccurate because the leukemia had been growing back in pockets. Even though he was still fighting, his blog revealed a greater

28 Vivekanandanda is considered to be a major force in the revival of Hinduism in modern India.
sense of fate: “The mylotarg bag has just been hung; let’s pray for the best. Whatever happens in the end is God’s wish regardless.”

Sameer continued to fight for several months after his relapse, and he continued to blog prolifically. His posts were still positive, but sounded slightly different and more reflective: “Looking back at my life so far, anything significant I’ve achieved—getting into Stanford, starting my current company five years ago with only $4K, just to cite two examples—have been in the face of much greater odds. In fact, I have always thrived under pressure and cherished nothing more than beating the odds. Of course, a key difference is that I can’t simply outwork someone or run through a wall to achieve a goal here. I can only maintain a positive outlook and keep trying to absorb all the love that you all are sending my way…. I’m still overwhelmed by the love and it brings me to tears when I think of it.”

Over the next two months, Kumar’s posts were more frequent, a sign that Sameer’s condition was worsening. Kumar regularly updated the blog, describing that Sameer was in the ICU fighting for his life. On March 24, 2008, Kumar still managed to blog quickly, despite the fact that Sameer had a stroke and that his brain was affected. But after a valiant fight, Sameer passed away in March 2008. His last blog post was on February 11, 2008. Chatwani recalled his last days with Sameer: “During Sameer’s last week, we visited him at the University of Washington Hospital in Seattle a lot. We told him a lot of funny stories and we knew he was listening to us because he would squeeze our hands. He wasn’t conscious, but it was amazing for us to be able to spend that time with him.”

In line with Sameer and the team’s efforts, they shared Sameer’s memorial service via webcast. Over 200 global viewers watched live with 6,000 plus views in the first seven weeks after his passing. Sameer’s memorial photo slideshow was viewed over 6,000 times as well. Chatwani said: “We knew that there were thousands of people around the world that couldn’t be with us so we put everything online. The idea that we could use technology to break down barriers and boundaries was very powerful. It was our way of connecting Sameer’s friends and family from around the world to his memorial, which was a celebration of his life.”

Vinay received his transplant in the fall of 2007 as well. He made the hundred-day mark, which was what patients aimed for so as to be in the clear. But Vinay also relapsed soon after his transplant in early 2008. Vinay blogged less frequently, but Radhakrishnan recounted the details: “We knew it was serious. Vinay was a doctor so he knew what was going to happen, but he kept fighting anyway. And Sameer was off and on in really bad shape and in a coma in March, and passed away. That same week, Vinay was admitted into the ICU and they said he was going to die, so his entire 40-person family flew out, but somehow he pulled through. He stuck around and hung out and had a lot of quality time with his family.”

31 Patients with newly diagnosed AML treated with standard chemotherapy can achieve remission rates of 50% to 80%. Unfortunately, this remission lasts for an average of only one year, and most patients will relapse. AML is tougher to treat the second time around, and the treatments tend to cause substantial toxicity. Mylotarg is a new AML drug that induces remission in 30 percent of study patients. http://www.cancer.org/docroot/NWS/content/update/NWS_1_1xU_Mylotarg_Acts_as_a_%E2%80%9CTrojan_Horse%E2%80%9D_in_AML_Treatment.asp.
During the last few months, Vinay also underwent the Mylotarg chemotherapy treatment and alternative drug treatments. He faced a host of other health problems such as graft versus host disease (GVHD), a common complication of bone marrow transplants where immune cells in the transplanted marrow recognize the recipient as foreign and mount an attack. Vinay entered the ICU three times for acute kidney failure, acute liver failure, and excessive blood loss from the gut. After an equally valiant fight, Vinay passed away on June 25, 2008.

THE LEGACY

Through an integrated strategy that leveraged enabling technologies, sheer passion, and persistence, as well as an understanding that they could not succeed without the help of others, Team Sameer and Team Vinay together reached their goals of registering 20,000 donors. Chatwani reflected: “Big revolutions start with simple ideas and ordinary people. The notion that there are constraints is irrelevant. The biggest asset you have is to think clearly and take a very big idea and run with it.”

More Matches for Others

Beyond the teams’ success in registering 20,000 donors, they had left a legacy and started a revolution that would ultimately inspire many others and save many other lives. At the macro level, the campaign impacted the NMDP’s percentage of South Asians, increasing it from 1.1 percent to 1.9 percent.34 Blume added: “Moreover, retention rates for South Asians have improved to 50 percent. All of these things are driven by our visibility as an organization. We were so visible during Sameer’s and Vinay’s campaigns that people now recognize us.”

Moreover, of the over 24,000 registrants, 7,500 had been registered in the San Francisco Bay Area, and of those 7,500, 80 new matches were found for other leukemia patients. In 2008 alone, through the efforts of the two teams, 266 other individuals donated bone marrow and thus possibly 266 other lives were saved just from the efforts of Team Sameer and Vinay’s registration efforts.

One such registrant, Bay Area pharmacy student, Rina Mehta, heard about Team Sameer and Team Vinay through a friend who had encouraged her to register. Her friend sent her an invitation through Facebook, along with information for a drive in Fremont, California and she decided to check it out. Mehta said: “It was so easy to register that I decided to do it and I told everyone I knew to do the same, including my parents.” Within six months, Mehta received a phone call from AADP asking her to do more testing because she was a potential match for another patient. “I was nervous,” she said. Mehta became a peripheral blood stem cell donor to an 18-year-old male leukemia patient because she didn’t qualify as a bone marrow donor due to her weight of 95 pounds. “I decided to donate because my fear and any inconvenience it might cause me paled in comparison to what he was going through.” On the campaign itself, Mehta said: “I don’t think there was an Indian person in the community that didn’t know about the campaign and what was happening, it was that widespread.”

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34 Asia Blume, Asian American Donor Program.
Passing the Torch to Others: Open Sourcing

Perhaps most importantly, the two teams had started a revolution that could be passed onto others who faced similar situations: “We want to give people everything that we did so they can just plug into it, use it and add onto it,” said Gaitonde. “We’re looking to open source everything that we did to help others in similar situations.” For example, Chatwani created a presentation that outlined the story and provided key lessons from their campaign called “The Eight Lessons”: 1) Stay focused, develop a single goal; 2) Tell your story; 3) Act, then think; 4) Design for collaboration; 5) Empowerment marketing; 6) Measure one metric; 7) Try, fail, succeed; 8) Don’t ask for help; require it. (Exhibit 15).

After seeing the success of Team Sameer and Team Vinay, many patients had contacted the two teams for advice. One such example of such inspiration and transfer of knowledge is Project Michelle. Michelle Maykin is a 27-year-old woman who was diagnosed with AML in February 2007. Her husband (boyfriend at the time), Van Le, was Vinay’s college roommate and had helped with Vinay’s donor drives and then started “Project Michelle” or a website and campaign dedicated to registering Vietnamese and Thai bone marrow registrants. When Michelle relapsed, in 2008 Le contacted Radhakrishnan from Team Vinay. “Talking to them helped us in terms of setting our goals, our organization and our strategy. We set our registrant goal at 15,000. We set up our donor drive organization in different cities in the same way that Team Sameer and Vinay did. We copied their empowerment marketing strategy. Because of them, we were able to get up and running in six or seven days instead of much longer if we didn’t have them as an example.”

Project Michelle was a big success, registering 18,000 people by 2009. Ultimately, Michelle did not find a match, and opted to receive a blood cord transplant in November 2008, but as of early 2009, was doing well and received the green light to head home to the Bay Area in early 2009. Le added: “Even after Michelle switched over to cord blood transplants, we asked people to keep working on bone marrow registrants because it was never just about Michelle.” In fact, Michelle’s team knew of at least two registrants from their own campaign that went on to become donors for other patients.

As Michelle and Van Le prepared to pack their car and drive back from Seattle to the Bay Area, he reflected on their experiences: “It started with Vinay and Sameer, moved onto Michelle, and Michelle’s not going to be the last patient. We know so many others. And now that we’re in the cancer, leukemia, and bone marrow transplant community, we realize we’re part of a revolving circle. We’ve been contacted by so many people like Jodie Gee (www.savejodie.com) who has since found a donor. Another is Krissy Kobata at www.teamkrissy.com. It’s a collective effort. The teams are all working towards the same goal. Sameer and Vinay’s legacy lives on.”

* If any of you have a friend, family member, or acquaintance that has been diagnosed with leukemia, please refer to this website as one source of support: http://www.helpsameer.org/strategy/.

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35 Michelle is Vietnamese (mother) and Chinese (father), and her father was born in Thailand.
Exhibit 1

Acute Myelogenous Leukemia

Understanding AML
About 13,290 Americans are expected to be diagnosed with acute myelogenous leukemia (AML) in 2008. The chance of getting AML increases with age. However, children and adults of any age can develop AML. About one in five children with leukemia has AML. The goal of treatment for AML is to bring about a remission or to cure the disease.

The number of patients with AML who enter remission, stay in remission for years or are cured has increased significantly over the past 30 years.

Causes and Risk Factors
AML starts with a change to a single cell in the bone marrow. With AML, the leukemic cells are often referred to as blast cells.

Medical researchers are working to understand the cell changes that lead to AML.

Down syndrome and other uncommon genetic disorders such as Fanconi anemia and Shwachman-Diamond syndrome and others are associated with an increased risk of AML.

Some other risk factors associated with AML are:
- Some types of chemotherapy
- Radiation therapy used to treat other cancers
- Tobacco smoke
- Exposure to large amounts of benzene

Most people who have these risk factors do not get AML - and most people with AML do not have these risk factors.

You cannot catch AML from someone else. Very rarely, more cases of AML than would be expected are diagnosed within the same family. It is thought that children in these families inherit a gene that makes them more susceptible to developing AML. Research to improve the understanding of familial cancers and effective medical management of them is underway.

Signs and Symptoms
Some of the signs and symptoms for AML are common to many illnesses. Some changes that a person with AML may have are:
- Tiredness or no energy
- Shortness of breath during physical activity
- Pale skin
- Swollen gums
- Slow healing of cuts
- Pinhead-size red spots under the skin
- Prolonged bleeding from minor cuts
- Mild fever
- Black-and-blue marks (bruises) with no clear cause
- Aches in bones or knees, hips or shoulder.

The best advice for any person troubled by any of these symptoms is to see a healthcare provider.

**Treatment**

Patients with AML need to start chemotherapy right away. It is important to get medical care in a center where doctors are experienced in treating AML patients.

There are two parts of AML treatment, called induction therapy and consolidation therapy. The aim of induction therapy is to kill as many AML cells as possible and get blood cell counts back to normal over time. When the aim of induction therapy is achieved it is called a remission. A patient in remission feels better over time and leukemia cells can't be seen in his or her blood or marrow.

Induction therapy is done in the hospital. Patients are often in the hospital for three to four weeks. Some patients may need to be in the hospital longer.

Many different drugs are used to kill leukemic cells. Each drug type works in a different way to kill the cells. Combining drug types can strengthen the effects of the drugs. New drug combinations are being studied. Two or more chemotherapies are usually used together to treat AML. Some drugs are given by mouth. Most chemotherapies are given through a catheter placed into a vein, usually in the patient's upper chest.

The first round of chemotherapy usually does not get rid of all the AML cells. Most patients will need more treatment. Usually the same drugs are used for more rounds of treatment to complete induction therapy.

More treatment is usually needed even after a patient with AML is in remission. This second part of treatment is called consolidation therapy. It is needed because some AML cells remain that are not found by common blood or marrow tests. Consolidation therapy is also done in the hospital. As with induction therapy, patients may be in the hospital for three to four weeks, or sometimes longer. Consolidation therapy may include chemotherapy with or without an allogeneic stem cell transplant or autologous stem cell transplant.

**Follow-Up Visits**

Patients who are in remission still need to see the doctor regularly for exams and blood tests.
Bone marrow tests may be needed too. The doctor may recommend longer waits between follow-up visits if a patient continues to be disease-free.

**Refractory Leukemia and Relapsed Leukemia**

Some patients still have AML cells in their marrow after treatment. This is called refractory AML. With refractory AML, drugs that were not used to treat the patient's AML in the first part of treatment may be given. Allogeneic stem cell transplantation also may be used for certain patients.

For patients who relapse, the same or different drugs may be given, or stem cell transplantation may be used. A drug called gemtuzumab ozogamicin (Mylotarg®) is being used to treat some older patients who have relapsed AML.

**Allogeneic Stem Cell Transplantation**

Chemotherapy used to treat AML also kills the healthy stem cells in the marrow. Allogeneic stem cell transplant is used to treat some AML patients.

There are two reasons for doing an allogeneic stem cell transplant:

1. To give strong doses of chemotherapy to kill more AML cells.
2. To give the patient the donor immune cells to attack any AML cells that remain.

When the donor cells attack the AML cells it is called graft versus leukemia or GVL. GVL is also called graft versus cancer.

Allogeneic stem cell transplant can be a high-risk procedure. For this reason, it may not be a good treatment for some AML patients. The decision to do a transplant depends on the patient's age and overall health, the chances that chemotherapy alone will cure his or her AML, and the patient's understanding of the benefits and risks of the transplant. Doctors will discuss these with patients and parents of young children with AML.

AML patients who have an allogeneic stem cell transplant are usually between the ages of 1 and 50 and are in remission. In addition, the patient needs to have a matched donor.

Doctors are studying a type of stem cell transplant called a nonmyeloablative stem cell transplant. This treatment may be helpful for older patients.

**Autologous Stem Cell Transplantation**

Patients who do not have a matched donor for a stem cell transplant may be given very high doses of chemotherapy and an autologous stem cell transplant instead. The goal of an autologous stem cell transplant is to restore the body's ability to make normal blood cells after high-dose chemotherapy.

**Disease and Treatment Side Effects**

Not all patients have side effects. However, chemotherapy and radiation therapy often affect a person's blood counts. The number of red cells may decrease (called anemia). Transfusions of
red cells (blood cells that are donated and given to the patient) are usually needed to increase the red cell count. Patients usually have a drop in the number of platelets. If a patient's platelet count is very low he or she usually needs a platelet transfusion to prevent or treat bleeding. A long-lasting and big drop in white cells may lead to an infection. Such infections are usually treated with antibiotics, until the normal white cell count goes up and the infection clears up. Patients with an infection may also have coughing, sore throat, pain when urinating, or frequent loose bowel movements. Or, fever or chills may be the only signs of infection.

To lower the risk of bacterial, viral and fungal infections, patients, visitors and medical staff need to wash their hands well. Also, the patient's central line must be kept clean and patients should follow all medical advice for taking care of their teeth and gums.

Complete blood counts are usually done throughout treatment. If the red cell counts or platelet counts are too low transfusions may be necessary. Growth factors are sometimes given to increase the number of white cells if they are too low. G-CSF (Neupogen® or Neulasta®) and GM-CSF (Leukine®) are drugs that increase white cell counts. Your doctor may talk about neutropenia (a lower than normal neutrophil count) and absolute neutrophil count or ANC, which is the number of white cells that are neutrophils.

Other side effects of treatment include: mouth sores, rashes, dry mouth, diarrhea, nausea, constipation, hair loss, vomiting, or changes in the way certain foods taste. Drugs or other therapies may be helpful to prevent or treat nausea, vomiting and other side effects.

Chemotherapy may cause the amount of uric acid to increase in the blood of some AML patients. (Some patients also have a buildup of uric acid from the disease itself.) Uric acid is a chemical made in the body. A high level of uric acid can cause kidney stones. Patients with high uric acid levels may be given a drug called allopurinol (Aloprim®, Zyloprim®) by mouth. Another drug used to treat high uric acid levels is called rasburicase(Elitek®), which is given by vein.

Clinical Trials

Clinical trials are used to study new drugs, new treatments or new uses for approved drugs or treatments. Research has contributed to the growing number of patients with AML who enter remission, stay in remission for years or are cured. One of the challenges for future research is to develop treatments that help more patients.

Scientists are trying to create new drugs or find them from natural sources. They are also studying new combinations of drugs already being used. Scientists are studying ways to boost the body's natural defenses, called immunotherapy. The goal is to kill or prevent the growth of AML cells.

Scientists are studying a type of stem cell transplant, called a nonmyeloablative stem cell transplant.

Scientists are studying cytokines, natural substances made by cells. Cytokines can also be made in the lab. They can be used to help restore normal blood cell counts during treatment or boost the immune system to better attack the leukemia cells.
Leukemia-specific therapy, based on a patient's specific subtype of leukemia, such as the type of chromosome changes, is being studied.

The AML cells of some patients are not as easily killed by drugs as those of other patients. This is called drug resistance. Scientists are trying to understand why some AML cells are resistant to the effects of chemotherapy. This will help them develop better treatments.

Scientists are studying the exact genetic changes that cause a normal cell to become an AML cell. This research is leading to the development of new treatments. These treatments could block the effects of cancer-causing genes (called oncogenes).

Gentuzumab ozogamicin (Mylotarg®) is FDA-approved to treat CD33 positive AML patients in first relapse who are 60 years of age or older and who are not considered candidates for cytotoxic chemotherapy. This drug is being studied in combination with other drugs to treat relapsed AML and is also being studied in combination with all-trans retinoic acid (ATRA) and arsenic trioxide (ATO) to treat acute promyelocytic leukemia.

Some other drugs under study for future use in AML treatment include:

- Farnesyl transferase inhibitors, for example tipifarnib (Zarnestra®) or lonafarnib
- FLT-3 inhibitors
- Proteasome inhibitors, such as bortezomib (Velcade®)
- Multi-drug Resistance Modulators, such as cyclosporine A or PSC-833
- Antisense molecules (Genasense®, GTI-2040)
- Hypomethylating agents, such as decitabine (Dacogen®)
- Histone deacetylase inhibitors, such as depsipeptide.

Exhibit 2
Strategy

Instant Brand
Quickly generate awareness of HelpVinay & HelpSameer
  • Social Media
  • Traditional Media

Mass Micro-Mobilization
Drive action amongst as many South Asians as possible
  • Education
  • Registration

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
Sameer Bhatia first blamed his symptoms, which arrived just before the monsoon season in India, on the 100-degree weather and humidity.

"I started feeling nausea, lack of appetite and my heart was racing when I had just climbed a flight of stairs," the Mercer Island native said. He ordered heart tests and instead found that his white blood cell count had rocketed. He was diagnosed with leukemia.

If he wanted treatment in the United States, he would have to fly to America that night, his doctor said. The Bhatias booked the last two tickets on a flight that May evening and arrived at a hospital in New Jersey 40 hours later. Bhatia had a bone marrow biopsy the next day to confirm his diagnosis.

The doctor verified two things: Bhatia had acute myelogenous leukemia and he needed a bone marrow transplant. But a bone marrow transplant can be an insurmountable challenge for people of South Asian descent -- they have just a 1 in 20,000 chance of finding a compatible donor, according to the National Marrow Donor Program. Caucasians have a 1 in 15 chance of finding a match.

Of the 6 million people registered in the donor program, just 1.5 percent are South Asian. At 31, Bhatia is used to traveling for work but not for health. He grew up on Mercer Island, graduated from Mercer Island High School in 1993 and attended Stanford for his undergraduate degree. He and his wife, Reena, live in San Francisco and routinely fly to Mumbai (formerly Bombay) where they manage a leg of their company, which makes cell phone games.

The entrepreneur faced his prognosis like a business challenge. He joined Vinay Chakravarthy, a South Asian in Boston who also has leukemia, in a national bone marrow registry drive. Now back on Mercer Island and living with his parents while he receives treatment at the Fred Hutchinson Cancer Research Center, Bhatia is encouraging Seattleites to register in hopes he will improve his odds for survival.

Exhibit 4
Bone Marrow and Peripheral Blood Stem Cell (PBSC) Donation Process

The first step to becoming a bone marrow donor is to join the National Marrow Donor Program (NMDP) Registry. Doctors search our Registry to find donors for their patients who need a transplant. If a doctor selects you as a suitable match, you will be asked to donate either bone marrow or blood cells.

1. Join the Registry
Anyone age 18 - 60 who meets the health guidelines and is committed to helping any patient in need may join. First, you complete a short health questionnaire and sign a form stating you understand what being on our Registry means. Then you give a small blood sample or swab of cheek cells to be tested for your tissue type, and this information is added to the Registry.

2. Stay committed and available
Doctors search our Registry to find a donor whose tissue type matches their patient's. If you are chosen, we will contact you. If you agree to proceed, we will schedule more testing.

3. Attend an information session
We will invite you to learn about the donation process, risks and side effects. Please feel free to bring a friend or family member to your information session. We will let you know if the doctor has requested a donation of cells from bone marrow or cells from circulating blood (known as a PBSC donation). Then you can decide whether or not to donate.

4. Receive a physical exam
If you agree to donate, you will have a physical exam to discover if donating would pose any special risks to you or the patient.

5. Bone marrow donation
Bone marrow donation is a surgical procedure. While you receive anesthesia, doctors use special, hollow needles to withdraw liquid marrow from the back of your pelvic bones. Many donors receive a transfusion of their own previously donated blood.

6. Side effects and recovery of bone marrow donation
You may feel some soreness in your lower back for a few days. Most donors are back to their normal routine in a few days. Your marrow is completely replaced within four to six weeks.

6. Side effects and recovery of PBSC Donation
You may experience headache or bone or muscle aches for several days before collection, a side effect of the filgrastim injections. These effects disappear shortly after collection.

7. Follow-up
We will follow up with you until you are able to resume normal activity, and will call you annually for long-term follow up.

Source: National Marrow Donor Program,
Exhibit 5
Sameer Bhatia and Vinay Chakravarthy

Front page photos from Sameer’s website:

Front page photo from Vinay’s website:

Exhibit 6
Websites

About Sameer

Our friend, Sameer Bhalla, was just diagnosed with Acute Myelogenous Leukemia (AML), which is a cancer of the blood. He is in urgent need of a bone marrow transplant. Sameer is a Silicon Valley entrepreneur, is 31 years old and just got married in 2005. His diagnosis was confirmed just weeks ago and caught us all by surprise.

Another friend of ours, Vinay, was also diagnosed with AML and also requires a transplant (maybe you may already be familiar with Vinay's campaign). We have teamed up with Team Vinay in order to build greater awareness of how you can help.

Help Sameer
Attend an upcoming bone marrow drive and join the registry

Help Vinay!
URGENT! JOIN THE MARROW REGISTRY!!!

PBS Documentary on Vinay

Vinay is profiled in an upcoming documentary that will air on PBS on

The Truth About Cancer will feature three stories of Boston-based Ca challenges and navigating the healthcare system to try and obtain the Cancer Center and their vast amount of resources is also featured.

Details on the program can be found here

God Bless You

On May 3rd, 2008 Anonymous says:

Dear Vinay:
Please post your updated progress as we are all wondering how you
Dear Friends,

Please take a moment to read this e-mail. My friend, Sameer Bhatia, has been diagnosed with Acute Myelogenous Leukemia (AML), which is a cancer of the blood. He is in urgent need of a bone marrow transplant. Sameer is a Silicon Valley entrepreneur, is 31 years old, and got married last year. His diagnosis was confirmed just weeks ago and caught us all by surprise given that he has always been in peak condition.

Sameer, a Stanford alum, is known to many for his efforts in launching the American India Foundation, Project DOSTI, TiE (Chicago), a microfinance fund, and other causes focused on helping others. Now he urgently needs our help in giving him a new lease on life. He is undergoing chemotherapy at present but needs a bone marrow transplant to sustain beyond the next few months.

Fortunately, you can help. Let's use the power of the Net to save a life…something that couldn’t be done years ago, but is now possible.

**Three Things You Can Do**
(Click here for more details online)

1. **Please get registered.**
   Getting registered is quick and requires a simple cheek swab (2 minutes of your time) and filling out some forms (5 minutes of your time). Registering and even donating if you’re ever selected is VERY simple.

   Another friend of ours, Vinay, was also diagnosed with AML and requires a transplant. We have joined forces with Team Vinay ([www.helpvinay.org](http://www.helpvinay.org)) in order to get South Asians registered in the bone marrow registry. Both Sameer and Vinay need a match from another South Asian, however, very few South Asians are actually in the registry and this makes it difficult for doctors to find them a match. This is why we need your help.

   We are supporting Team Vinay in organizing drives nationwide, and I need you to get registered by visiting a local drive. Drives are currently taking place all around the country, including throughout California, Washington, Michigan, Illinois, New York and many other states. Please see the full list of locations here: [http://www.helpvinay.org/dp/index.php?q=event](http://www.helpvinay.org/dp/index.php?q=event).

2. **Spread the word.**
   Please share this e-mail message with at least 10 people (particularly South Asians), and ask them to do the same. Please point your friends to the local drives and ask them to get registered. If you can, sponsor a drive at your company or in your community. Drives need to take place in the next 2-3 weeks to be of help to Sameer and Vinay.

   Please use the power of your address book and the Web to spread this message – today more than ever before, we can achieve broad scale and be part of a large online movement to save lives.

3. **Learn more**
To learn more, please visit http://www.nickmyers.com/helpsameer. The site includes more details on how to organize your own drive, valuable information about AML, plus FAQs on registering. Please visit http://www.helpvinay.org/dp/index.php?q=node/108 for more information on the cities where more help is needed. Another past success story from our community is that of Pia Awal’s; please read about her successful fight against AML at www.matchpia.org.

Thank you for getting registered to help Sameer and Vinay win their fight against leukemia – and for helping others who may face blood cancers in the future.

 Truly,  

Robert  

* * * * *

**FAQs on Bone Marrow Transplant**  
*(more details at http://www.helpvinay.org/dp/index.php?q=node/18)*

**What are the actual chances of finding a suitable marrow or stem cell donor, and how do I know if I’m a match?**

The odds of finding a match vary, but the best case scenario for South Asians is 1 in 20,000. If you are found to be a possible match, you will be contacted by the National Registry or your local center. You will be presented with the option of proceeding to the next level of testing.

**How my marrow is collected?**

The most common procedure is peripheral blood stem cell collection. You are given injections to support overproduction of marrow, which is then released into your circulating blood. The cells are collected by removing blood from a vein in your arm during a simple procedure. This is very similar to donating blood – isn’t it amazing that it’s that easy to save someone’s life?!

Source: Robert Chatwani.
Exhibit 8
Dummies Guide to Hosting a Bone Marrow Drive at Work Excerpt

“10 Simple Steps—You Can Do It!

Let’s find Sameer and Vinay a match! Hosting a bone marrow registration drive at work takes some effort, but your drive can be a big success with the right planning and coordination. This playbook is designed to make it as easy as possible for you. Since each company is organized differently, think of this as a general guide. The various steps are laid out in sequence, and sample emails are included for you to customize for your own use. Replace the text in red with your own text…”

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
Exhibit 9
Dragonfly Model

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
A year ago, he was enjoying life with his wife & friends and giving back to the community.

This is our friend Sameer.

Vinay needs You to improve his chances.

South Asians with leukemia have a 1 in 20,000 chance of finding a donor match.

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
Exhibit 11
Online Video

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
Sameer Bhatia, the founder of barter site MonkeyBin and mobile gaming company Octane Technologies, has a new challenge ahead of him. The 31-year-old Stanford grad has been diagnosed with acute myelogenous leukemia (AML), and is in need of a bone marrow transplant to survive. Friends of the entrepreneur have organized several bone marrow drives around

Exhibit 13
Letter from Barack Obama

June 27, 2007

Dear Friends:

Vinay Chakravarthy is 28 years old, a son, a husband, and an aspiring doctor. Vinay has been diagnosed with Acute Myeloid Leukemia, and we can save his life.

Vinay’s cancer can be cured with a simple bone marrow transplant. As a South Asian, Vinay has only a 1 in 20,000 chance of finding a bone marrow match, which is his only chance to survive. We must encourage all of our friends and family inside and outside the South Asian community to register, commit to donating, and do so immediately, as Vinay needs this match by July 10.

I commend Team Vinay’s effort to obtain 20,000 registered donors by July 10. To date they have reached 6,904 donors, so we have a lot of work to do. Together we can reach out to communities across the country and remind them that we—members of Vinay’s family, community, and country—have a responsibility to help. We should all see ourselves in Vinay and realize that he deserves the same support we would wish for a member of our own family or even ourselves.

I support Team Vinay’s continued good work and share my hope that we can come together to help Vinay.

Sincerely,

Barack Obama
United States Senator

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
Exhibit 14
YouTube Video of Sameer’s Transplant

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.
The 8 Lessons

1. Develop a clear goal.
2. Tell your story.
3. Act, then think (big).
4. Design for collaboration.
5. Empowerment marketing.
6. Measure one metric.
7. Try, fail, succeed.
8. Don’t ask for help. Require it.

Source: Robert Chatwani presentation to Stanford GSB course, January 2009.