Josh Hardy and the #SaveJosh Army: How Corporate Risk Escalates and Accelerates through Social Media

By David F. Larcker, Sarah M. Larcker, and Brian Tayan
April 14, 2014

INTRODUCTION
Social media is the phenomenon by which individuals use technology to create, gather, and share information directly with peers. Social media differs from traditional media in that content does not move unidirectionally from a centralized outlet to the consumer, but instead in a networked pattern among consumers. Furthermore, information does not remain static as it moves through social media outlets. Each user has the opportunity to actively alter message and tone as content is shared.

There is extensive evidence to suggest that social media has fundamentally changed the relationship between corporations and constituents. For example, a 2012 survey by Edelman finds that “listening to customers” for the first time is considered equal in importance to providing a high-quality product or service when it comes to establishing trust.1 Consumers expect to be able to engage with companies through social media, and the vast majority of consumers believe that direct engagement between company and consumer improves brand image.2 Furthermore, there is evidence to suggest that emotional perception, and not just information, is shaped by social media interactions. A 2014 paper by researchers at the University of California at San Diego finds that emotions expressed online can be contagious, with negative Facebook posts likely to trigger negative responses and positive posts likely to trigger positive responses.3 According to lead author James Fowler, “Our study suggests that people are not just choosing other people like themselves to associate with but actually causing their friends’ emotional expressions to change.”4

To understand the implications of social media communication on corporate reputation, consider the story of Josh Hardy.

JOSH HARDY
In February 2014, Josh Hardy, a 7 year-old boy from Fredericksburg, Virginia and four-time cancer survivor, was hospitalized with adenovirus following a bone marrow transplant. Adenovirus is a common virus among children and, while typically not serious, has severe implications for patients undergoing cancer treatment because of their weakened immune systems. To fight the disease, Josh was prescribed a standardized regimen of antiviral medicine cidofovir. The treatment unfortunately caused kidney failure, and Josh fell into critical condition.

Doctors informed Josh’s parents of an experimental antiviral medication called brincidofovir that was shown to be effective in treating infections such as adenovirus but without the toxic side effects that trigger organ failure. Brincidofovir was being developed by Chimerix, a small biotechnology company in Durham, North Carolina that went public in April 2013 to finance Phase 3 testing and bring the drug to market.

Despite requests from Josh’s family and doctors, Chimerix declined to release brincidofovir. The company claimed that the drug was expensive to produce.5 It had discontinued its formal “compassionate use” program two years before in order to concentrate its resources on clinical testing.6 Furthermore, granting investigational drugs to severely ill patients can skew drug efficacy results, undermining the clinical trial and delaying U.S. Food and Drug Administration (FDA) approval.

On March 4, Josh’s parents sent an email to friends and family asking for help: “If anyone with influence can help us convince the Chimerix Inc
Josh Hardy and the #SaveJosh Army: How Corporate Risk Escalates and Accelerates through Social Media

To release the drug for compassionate care for our son, we would be forever grateful.” On March 7, a recipient of that message launched a Facebook page and Twitter feed, titled #SaveJosh (see Exhibit 1). That same day, the story was picked up by the local media (see Exhibit 2).

The next day, a Facebook user posted an email from CEO Kenneth Moch to the #SaveJosh Facebook page, explaining the company’s position and reaffirming the decision not to release the drug. Moch claimed that the company “continues to receive many requests every week from around the world for this experimental drug” and that its “limited resources are dedicated to successfully completing the [clinical] trial” and bringing the drug to market (see Exhibit 3).

Rather than quell the movement, the CEO’s response added fuel to the fire. According to one Facebook follower: “Chimerix’s latest response [is] unfortunate but not unexpected. Do not relent SaveJosh.” Another wrote that, “Chimerix makes me sick! They released an article yesterday that they are accepting participants for the phase 3 trials... I do not understand why Josh cannot be part of this!... We will continue to email and call for Josh... Hoping and praying that they make the right decision.” To add pressure to the company, a user posted the CEO’s home address and phone number. Another listed the names of the company’s board of directors (see Exhibit 4).

Over the next few days, the story accelerated. On March 9, it was featured on CNN and Fox News. By the end of the day, the story was trending at number five nationally among all stories on Twitter, and the #SaveJosh Facebook page had over 10,000 likes.

March 10, national headlines took an increasingly negative tone. Fox published a story entitled, “Drug Company Refuses to Help 7-Year Old Boy.” USA Today wrote that, “Thousands Beg Company to Give Medication to Sick Boy.” The story captured even greater attention when the Max Cure Foundation offered to make a donation to cover the full cost of the treatment only to be refused by Moch. According to a representative:

\[I \text{ told him that we had the $50,000 dollars that...}\]

I thought he was claiming he needed to supply the drug. He told me it isn’t about the money. He told me that it’s all about the ethics [of supplying one child but not others].

The representative also claimed that Moch hung up the phone on him. Public response to the story was intense. Moch received death threats, and police security was called to the company’s office to protect employees. Chimerix automatically forwarded incoming phone calls to voicemail.

March 11, after the close of business, Chimerix announced a change of position. The company would provide brincidofovir to Josh as part of a new 20 patient open-label study, coordinated with the FDA. Unlike in a clinical trial which is double-blinded, both doctors and patients in an open-label study know that the drug is being administered. According to a company press release:

Josh Hardy’s story brought to public attention the often-devastating impact of adenovirus infection, and helped accelerate a discussion between the FDA and Chimerix regarding the need for additional clinical development to assess brincidofovir’s potential in adenovirus infection. This study is expected to begin with Josh Hardy as the first patient enrolled on Wednesday, March 12, 2014.

The following day, the company’s stock price increased 18 percent, in part because the news was interpreted as a vote of confidence in the drug by the FDA (see Exhibit 6).

While news that Josh would receive the drug brought relief and appreciation among #SaveJosh followers, CEO Moch noted in an interview that he and his employees experienced “the dark side” of social media: “This reached a public social media crescendo. I’m concerned by the actions of those who really need to look into their own hearts and souls.”

By the end of the month, Josh Hardy showed considerable improvement and was moved out of intensive care. According to Josh’s mother:

We have gone from dire circumstances to discussing with our doctors what we need to get Josh discharged from the hospital. We are so grateful...
that the company was able to find a way for Josh to receive the medicine. We witnessed an absolute miracle by the grace of God.10

April 9, Chimerix announced that M. Michelle Berrey (previously chief medical officer of the company) would replace Kenneth Moch as CEO. No reason for the transition was given.

WHY THIS MATTERS
1. The Josh Hardy story demonstrates the potentially severe impact that social media can have on corporate reputation. And yet according to survey data, only 32 percent of companies monitor social media to detect risks to their business activities.11 Why aren’t more companies prepared to deal with reputational risks that emerge through online channels?
2. The Josh Hardy story is one of reputational risk, and yet it is fairly easy to extrapolate how social media could trigger similar outcomes across a broad range of corporate risk factors, including product quality, customer service, supplier activities, and employee malfeasance. How should information compiled from social media outlets be used to supplement a company’s comprehensive risk management program?
3. The board of directors relies on management to develop and implement programs to mitigate organizational risk. And yet at the same time, the board of directors is responsible for ensuring that these activities are carried out effectively. Is the Josh Hardy story a board-level issue? If so, at what point did it become one?
4. The social media uproar regarding Josh Hardy exploded in a very short period of time—five days. This suggests that boards and senior management teams need to be prepared to respond to social media stories that develop with unusually rapid velocity. If Chimerix were your company, what would you have done differently? ■

David Larcker is Director of the Corporate Governance Research Initiative at the Stanford Graduate School of Business and senior faculty member at the Rock Center for Corporate Governance at Stanford University. Sarah Larcker is Vice President of Account Planning at Digitas Health. Brian Tayan is a researcher with Stanford’s Corporate Governance Research Initiative. David Larcker and Brian Tayan are coauthors of the books A Real Look at Real World Corporate Governance and Corporate Governance Matters. The authors would like to thank Michelle E. Gutman for research assistance in the preparation of these materials.

The Stanford Closer Look Series is a collection of short case studies that explore topics, issues, and controversies in corporate governance and leadership. The Closer Look Series is published by the Corporate Governance Research Initiative at the Stanford Graduate School of Business and the Rock Center for Corporate Governance at Stanford University. For more information, visit: http://www.gsb.stanford.edu/cldr.

Copyright © 2014 by the Board of Trustees of the Leland Stanford Junior University. All rights reserved.

---

4 Inga Kiderra, “Facebook Feelings are Contagious, Study Shows,” UC San Diego News Center (March 12, 2014).
5 Some estimates placed the cost at $50,000 per patient but this number was not verified by the company. See Isabel Markham, “Why Drug Company Chimerix Is Denying Meds to a Dying Seven-Year Old,” Bustle.com (March 7, 2014).
6 Generally, the FDA does not allow patients to access investigational drugs unless the patient is enrolled in a clinical trial. However, an exception is granted for patients who are critically ill, known as “compassionate use.” Compassionate use programs are established only at the discretion of the company. Because investigational drugs are expensive to manufacture and insurance companies typically will not reimburse their cost, compassionate use programs offer very limited supply and distribution is tightly restricted.
11 The Rock Center for Corporate Governance at Stanford University and The Conference Board, 2012 Social Media Survey.
EXHIBIT 1 — #SAVEJOSH FACEBOOK PAGE LAUNCHED

[Image of the #SaveJosh Facebook page]

Josh Hardy and the #SaveJosh Army: How Corporate Risk Escalates and Accelerates Through Social Media
Op-Ed: Fredericksburg first-grader fighting for his life

Fredericksburg - Josh Hardy, a seven-year-old boy, is currently fighting for his life. Josh is suffering from a rare viral disease. His family have put out an appeal for help.

When he was nine months old, Josh Hardy was diagnosed with a malignant rhabdoid tumor of the kidneys. It is a highly aggressive, rare form of cancer that only 15 children are diagnosed with each year. Two years ago Josh Hardy defeated the cancer
EXHIBIT 3 — CEO EMAIL POSTED TO FACEBOOK

Five years ago, early in brincidofovir’s clinical development pathway, Chimerix began receiving requests from physicians for the emergency use of brincidofovir, in patients with many different viral infections, and we were able to supply brincidofovir for relatively small numbers of these requests. The volume of requests accelerated significantly, prompting Chimerix to establish a formal Compassionate Use program.

As our small company progressed to larger and more complex efficacy and safety trials designed to gain FDA approval of brincidofovir, we made the difficult decision two years ago to cease our Compassionate Use program and focus on earning FDA approval. This is the only path to making brincidofovir widely available to those who need it in the fastest manner allowed.

Our limited resources are dedicated to successfully completing the SUPPRESS trial and submitting the safety and efficacy data that would allow for brincidofovir to become available to physicians and patients in the US and, ultimately, around the globe. Each one of us at Chimerix is committed to achieving this goal and thereby enabling access to this potentially life-saving drug.

We continue to receive many requests every week from around the world for this experimental drug. The great need for access to brincidofovir drives our commitment to seeing the Phase 3 trial to its completion and to ultimately providing what we believe is an important new medicine to people in need.

Sincerely,
Kenneth Moch

********************************************************************
Kenneth L Moch
President & CEO
Chimerix, Inc.
2505 Meridian Parkway
Suite 340
Durham, North Carolina 27713
EXHIBIT 4 — PUBLIC RESPONSE ON FACEBOOK

#SAVE JOSH
Savejosh shared William R. Burns’s status.
March 8

Chimerix’s latest response. It is unfortunate but not unexpected. Do not relent SaveJosh

Missy Jones: Chimerix makes me sick! they released an article yesterday that they are accepting participants for the phase 3 trials...... I do not understand why Josh can not be part of this! I sent a second email referencing this article asking this very question..... We will continue to email and call for Josh.... Hoping and praying that they make the right decision.
Like · Reply · #58 · March 8 at 8:38pm

#SAVE JOSH
Savejosh
March 8

Keep Calm and TWEET ON
#SAVEJOSH

Silence DoGood II According to whitepages.com: Kenneth I. Moch’s home number is (919) 240-4423; his address is 200 Arcadia Lane, Chapel Hill, NC.
Like · Reply · #31 · 21 hours ago

#SAVE JOSH
Savejosh shared Mark Kroh’s status.
March 8

Do you know any of these people on the Chimerix board of directors? We are continuing to fight for Josh, but we need to get in contact with people who have leverage.

Chimerix, INC.

Kenneth Moch – CEO
Joseph Schepers – Executive Director IR and Corporate Communications
Lilian Stern – Investor Contact
Timothy Trost – Sr Vice President, CFO
M. Michelle Berrey – Chief Medical Officer
Linda Richardson – Chief Commercial Officer *** BA from Penn, worked for SmithKline
Michael Rodgers – Chief Development Officer ***did post doc at St. Judes
Herve Mommeja-Marin – VP Clinical Research

Board of Directors
Ernest Mario, PhD, Chairman
Chairman and CEO, Capnia, Inc.

Farah Champs, Director
Managing Director, Alta Partners

Martha J. Demski, Director
Senior Vice President and Chief Financial Officer, Ajinomoto Althea, Inc.
EXHIBIT 5 — NATIONAL HEADLINES

Fox News is joining in Josh’s fight for life, asking Chimerix to release the lifesaving drug he needs to survive. Please share Josh's story with all your friends!


Exhibit 5 — National Headlines

Drug company refuses to help 7-year-old boy
Cancer victim battling curable virus

Thousands beg company to give medication to sick boy

A Virginia family’s plea to get a 7-year-old cancer survivor with a B cell leukemia cancer the drug.

Like · Comment · Share

We are so very appreciative of the media coverage and to know that so many people are supporting Josh and his fight to survive!

Like · Comment · Share

JOSH HARDY AND THE #SAVEJOSH ARMY: HOW CORPORATE RISK ESCALATES AND ACCELERATES THROUGH SOCIAL MEDIA
EXHIBIT 6 — CHIMERIX STOCK PRICE REACTION

March 7: Josh Hardy social blitz begins

After COB March 11: Chimerix releases drug for compassionate use