The Power of Storytelling & Social Media in Moving Patient Safety Issues

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Patients share their medical harm stories with Consumers Union
Stories put a human face to the problem of medical harm and empower us to make change

• Stories show the real impact of patient harm on patients & family members due to hospital infections, medical errors, implants, and doctors

• Stories help us identify people who will work with us to improve patient safety

• Stories help us find people willing to share their story with media & policymakers
Real People, Real Stories
Hip & Knee Implants

• We collected nearly 3,000 stories about hip & knee implants
• We interviewed dozens and featured their stories on our website
• We asked them to take action for hip & knee warranties
We share patients’ medical harm stories with Congress

- Last year, during the last stretch to send final medical device safety legislation to the President, we sent congressional staffers a person’s story each day asking them to keep real people in mind as they reconciled the bill.
We find stories for journalists to report on patient safety issues

*Consumer Reports'* “Dangerous medical devices,” investigation (May 2012)

**Lap-Band: Minimal testing**

In 2009, after many unsuccessful diets, Lisa Wilson, then 49, a pharmacy technician from Seattle, received the Lap-Band adjustable gastric band.

The implanted band constricted the size of the stomach to make it difficult to eat large quantities of food. In fact, the opening left to Wilson's stomach was so small that she had difficulty eating even small amounts of food. It also caused her to throw up almost every day.

But she stuck with it, losing 70 pounds, until a routine endoscopy in December 2010 revealed that the band had cut into her stomach lining and would have to be removed immediately. She developed a post-surgical infection that resulted in a partially collapsed lung and an eight-day hospital stay. Wilson says she has regained half of the weight she lost.

Lisa Wilson's weight-loss device had to be removed after it cut into her stomach.

Photo: Iris St. Clair

Charlee Mackenzie Retliff, of California, was 6 months old when she died in May 2010. She was diagnosed with C. diff while recovering from surgery to repair a hole in her heart. She died 95 days later after severe complications led doctors to remove part of her colon. **Links: What can stop fatal C. diff bacteria?**
Social Media: A Vehicle for Sharing Patient Safety Messages
Benefits of Using Twitter

• Easy to follow influential people in the patient safety field (journalists, state and federal health agencies, health professionals, advocates, academics)
• Stay up to date on patient safety news
• Deliver information instantly to our followers
• Engage with your audience – respond to people’s tweets, mention, retweet, use hashtags (#ptsafety)
• When a follower retweets you, and their followers retweet you, and their followers retweet you, your information/message reaches a bigger audience
Enhanced Exposure on Twitter

Paul Levy, Not Running a Hospital – 9,600+ followers

Scott Hensley, NPR: 18,600+ followers
Follow us: @CUsafepatient
• Share your patient story with us: [http://safepatientproject.org/share-your-story](http://safepatientproject.org/share-your-story)
• Contact: [dnunez@consumer.org](mailto:dnunez@consumer.org) / 512-477-4431 ext. 117
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