a Storytelling Campaign from

BRITISH COLUMBIA
The Best Place on Earth

ImmunizeBC

Today's Agenda

- **A History of the "I Have Immunity" Campaign**
  - Grassroots Advocacy
  - Social Media
- **The Value of Stories**
  - Evidence
  - Examples
- **Interactive Exercise: Find Your Story**
- **How YOU can get involved**
  - Sharing Your Stories
  - Spreading the Word

I HAVE immunity.com

Campaign History

- Developed with HELLO COOL WORLD.COM
- Launched in April 2011
- Aims to reflect the diversity of families in BC who support immunization
- Photos, videos and stories from individuals and families around the province
- A grassroots campaign using social media marketing

Campaign History

- **Grassroots Advocacy**
  - Community-based and community-driven
  - Responding to the concerns and needs of communities rather than orchestrating them
- **Social media marketing**
  - Social marketing = using marketing techniques to promote activities or behaviours that benefit communities and individuals
  - Social media marketing uses social media tools to disseminate messages about these desired behaviours
- **Examples: 65redroses.com**

65_REDROSES

Finding Our Advocates

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Advocate Stories

Laura and daughter Amanda (14)

Audra and children Alexandria (10) and Aaric (7)

Advocate Stories

Emily, with grandchildren Jada and Wynona

from the Skeetchestn Indian Band

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Sharing Stories

- **Offline**
  - Sharing your story in the community, for instance at a school or in a media article
  - In conversations
- **Online**
  - Through social media and I Have Immunity website
  - Allows for rapid dissemination and conversations
  - Anonymity

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Why Are Stories So Important?

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COMMENTARY

Narrative vs Evidence-Based Medicine—And, Not Or

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THE WEEK BEFORE THE US PREVENTIVE SERVICES TASK Force (USPSTF) released its recommendations against routine prostate screening for healthy men, celebrity patients including Joe Torre and Rudy Giuliani had already lined up to challenge the population-based recommendations. To promote their position that screening for prostate-specific antigen is lifesaving, these individuals relied on a powerful tool: their own personal narratives. However, the experts whose goal is to disseminate and translate population-based evidence will, in the name of science, shun individual stories. This one-sided use of narrative has played out repeatedly, from the USPSTF recommendations on screening mammography to the US Food and Drug Administration (FDA) labeling hearings on bevacizumab for advanced breast cancer.[1,2] Each time, those who espouse only evidence—without narratives about real people—struggle to control the debate. Typically, they lose.

Patients and families have a right to tell their stories. But what about scientists? Facts and figures are essential, but insufficient, to translate the data and promote the acceptance of evidence-based practices and policies. Narratives—in the forms of storytelling, testimonials, and entertainment—have been shown to improve individual health behaviors in multiple settings.[3,4] Moreover, evidence from social psychology research suggests that narratives, when compared with reporting statistical evidence alone, can have uniquely persuasive effects in overcoming preconceived beliefs and cognitive biases.[5] Therefore, although narrative is often maligned as anecdote and thus scrubbed from the toolbox of guideline developers, epidemiologists, and regulatory scientists, these experts should consider narrative to develop and translate evidence-based policies. This is especially important because the federal government has made substantial investments to improve the dissemination and translation of evidence from comparative effectiveness research and patient-centered outcomes research.[6]

Scientific reports are genuinely dispassionate, characterless, and ahistorical. But their translation and dissemination should not be. Stories are an essential part of how individuals understand and use evidence.[7] A narrative—defined as a cohesive story with a beginning, middle, and end—includes information about scene, characters, and conflict and raises questions and provides resolution.[8] From this framework, stories that link individuals and their experiences to evidence are tools to translate (not drive) science without introducing anecdotal bias.

Scientists can use narrative in at least 2 ways. First is in the form of counternarratives, designed to neutralize stories that promote disproven theories. Take the largely negated theories of a causal link between childhood vaccines and autism. As recounted by Offit in his book on this topic, a celebrity actor claimed that she does not need real science to know that the measles-mumps-rubella (MMR) vaccine triggered her son's autism: "[My son] is my science," she stated on television to thunderous audience applause.[9] Such narratives, challenging scientists who come to the table (or television studio) armed only with data, often succeed in the court of public opinion and weaken efforts to promote evidence-based health decisions.

When scientists encounter stories that promote unscientific approaches to health and health care, they should deploy an evidence-based counternarrative. The story of a mother in San Diego whose infant, too young for the MMR vaccine, became sick after exposure to an unvaccinated child with measles would add persuasive weight in a debate with the actor mentioned above.[5] These counternarratives may also be useful when the evidence addresses individual risks as well as effectiveness. The FDA's decision to remove breast cancer as an approved indication for bevacizumab was based not only on the absence of evidence to support its effectiveness in a general population but also on the relatively high risks of serious individual adverse effects, including death.[10] In such cases, real and personal narratives can be told that embody, with characters and action, the evidence of a risky intervention. The public needs to hear the stories of patients, and their families, who encountered a drug that offered hope but was ultimately ineffective and even dangerous.

Another role for scientific narrative is found within the process of evidence discovery and translation. Typically, experts present a "clean" version of their findings without any narrative about how they made sense of the data. This ful-

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JAMA 306(18)
November 2011

Narrative vs Evidence-Based Medicine– And, Not Or.

"Narratives—in the forms of storytelling, testimonials, and entertainment—have been shown to improve individual health behaviors in multiple settings."

What Works Best: Objective Statistics or a Personal Testimonial? An Assessment of the Persuasive Effects of Different Types of Message Evidence on Risk Perception

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Objective: In an experimental online study we compared the effects of different types of persuasive evidence in promoting the acceptance of a personal health risk. **Design:** 138 men who have sex with men (MSM) at risk for infection with the hepatitis B virus (HBV) were recruited via a range of websites and randomly assigned to one of 4 conditions (2 experimental and 2 control): narrative evidence (i.e., a personal account), statistical evidence (i.e., abstract prevalence data), mere assertion of increased risk, and no risk information. **Main Outcome Measures:** Narrative evidence was expected to more effective than statistical evidence in increasing MSM's perceived risk of infection with HBV as intention to obtain vaccination. **Results and Conclusion:** As predicted, perceptions of personal risk and intention to obtain vaccination against HBV were highest after presentation of narrative evidence, and risk perception mediated the effect of type of message evidence on intention. We propose that narrative evidence effectively promotes a sense of personal risk because it is less affected by defensive message processing resulting from the threat to important self-beliefs that seems inherent in health risk communication.

Keywords: risk perception, persuasion, message evidence, narratives, hepatitis B virus

Perceiving a personal risk is a major prerequisite for behavior change, according to major psychological theories of health behavior (e.g., Schwarzer, 2001). Reviews and meta-analytic studies demonstrate the pivotal role of risk perception in promoting precautionary behavior as observed in prospective and experimental studies (Floyd, Prentice-Dunn, & Rogers; Harrison, Mullen, & Green, 1992; Janz & Becker, 1984; Milne, Sheeran, & Orbell, 2000). In health education practice, however, increasing perceptions of personal health risk is easier said than done (cf. Rothman, Kelly, Hertel, & Salovey, 2003), mostly because people have many well-documented ways of discounting unwelcome messages (Weinstein, 2003). What is less known is how awareness and acceptance of a personal risk can be promoted without eliciting defensive responses in the message receiver. The aim of the present study is to contribute to a theory-based understanding of empirically effective health messages to promote risk perceptions by drawing on a body of work in communication science that is concerned with the influence of message evidence on persuasion (for an overview, see Reynolds & Reynolds, 2002). We in particular present a comparative test of health risk messages that offer different types of evidence to support a personal health risk assertion.

The Role of Evidence in Health Risk Communication

Including some form of proof for an assertion in a message consistently increases persuasion (Reinard, 1988). Message evidence comes in different forms that can be grouped into two general types: statistical, objective evidence and anecdotal, narrative evidence (cf. Perloff, 2003). Statistical evidence refers to the use of factual assertions and abstract data, such as pertinent prevalence estimates, to persuade message receivers that they are likely to be affected by a health problem. Narrative evidence, in contrast, includes concrete, emotionally interesting information, such as a first-person account of someone who came to experience a particular condition that may also affect the message recipient. The relative efficacy of narrative versus statistical evidence may be contingent on the relation between the content of a message and the initial position of the receiver (Slater & Rouner, 1996). Specifically, statistics have been found to be particularly persuasive when a message is preference-consistent, and is congruent with the views of receivers. In contrast, narrative evidence was most effective when a message was preference-inconsistent (Slater & Rouner, 1996). Health risk messages often convey potentially threatening information that is rarely received with enthusiasm if not sub-

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The reported study was made possible by a grant from ZonMw (grant number 23000032) to the first author.

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Health Psychology 27(1)
January 2008

What Works Best: Objective Statistics or a Personal Testimonial?

"Perceptions of personal risk and intention to obtain vaccination against HBV were highest after presentation of narrative evidence, and risk perception mediated the effect of type of message evidence on intention."

Annals of Internal Medicine | ORIGINAL RESEARCH

Culturally Appropriate Storytelling to Improve Blood Pressure

A Randomized Trial

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Background: Storytelling is emerging as a powerful tool for health promotion in vulnerable populations. However, these interventions remain largely untested in rigorous studies.

Objective: To test an interactive storytelling intervention involving DVDs.

Design: Randomized, controlled trial in which comparison patients received an attention control DVD. Separate random assignments were performed for patients with controlled or uncontrolled hypertension. (ClinicalTrials.gov registration number: NCT00875225)

Setting: An inner-city safety-net clinic in the southern United States.

Patients: 230 African Americans with hypertension.

Intervention: 3 DVDs that contained patient stories. Storytellers were drawn from the patient population.

Measurements: The outcomes were differential change in blood pressure for patients in the intervention versus the comparison group at baseline, 3 months, and 6 to 9 months.

Results: 299 African American patients were randomly assigned between December 2007 and May 2008 and 76.9% were retained throughout the study. Most patients (71.4%) were women, and the mean age was 53.7 years. Baseline mean systolic and diastolic pressures were similar in both groups. Among patients with baseline uncontrolled hypertension, reduction favored the intervention group at 3 months for both systolic (11.21 mm Hg [95% CI, 2.51 to 19.9 mm Hg]; $P = 0.012$) and diastolic (6.43 mm Hg [CI, 1.49 to 11.45 mm Hg]; $P = 0.012$) blood pressures. Patients with baseline controlled hypertension did not significantly differ over time between study groups. Blood pressure subsequently increased for both groups, but between-group differences remained relatively constant.

Limitation: This was a single-site study with 23% loss to follow-up and only 6 months of follow-up.

Conclusion: The storytelling intervention produced substantial and significant improvements in blood pressure for patients with baseline uncontrolled hypertension.

Primary Funding Source: Finding Answers: Disparities Research for Change, a national program of the Robert Wood Johnson Foundation.

Ann Intern Med. 2011;154:77-84. www.annals.org

For author affiliations, see end of text.

African Americans are 21% more likely than white persons to die of heart disease and 49% more likely to die of stroke (1). Despite many attempts to close racial and ethnic gaps in risks for cardiovascular diseases, such as hypertension, important disparities persist (2). Motivated by these findings, we sought to develop and test a novel, evidence-based, and culturally appropriate intervention to improve blood pressure control in African Americans.

Blood pressure control is complex for any patient with hypertension and requires long-term adherence to medication, diet, exercise, and medical follow-up. This complexity contributes to the widely documented poor control among patients in general (3) and African Americans in particular (4). African Americans are more likely to have hypertension, less likely to achieve control, and more likely to have end-organ damage than white persons (4). These differences in blood pressure control are partially explained by identifiable barriers, such as unhealthy diet and lack of exercise promoted by environmental factors (5), limited access to clinicians and medicine, distrust of the medical system (6, 7), and poor medication adherence (8, 9). However, interventions to overcome these barriers have had mixed results (10).

Programs that target vulnerable populations may fail for several reasons, including lack of cultural relevance. Although the resulting intervention may be conceptually sound, the lack of cultural relevance may decrease effectiveness (5). Emerging evidence suggests that storytelling, or narrative communication, may offer a unique opportunity to promote evidence-based choices in a culturally appropriate context. Stories can help listeners make meaning of their lives (11, 12), and listeners may be influenced if they actively engage in a story, identify themselves with the storyteller, and picture themselves taking part in the action (13). Because narrative communication can break down cognitive resistance to behavior-change messages (14), we hypothesized that it would be a suitable mechanism for ad-

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Summary for Patients I-24

Web-Only

Appendix
Appendix Tables
Appendix Figure
Material from intervention DVDs
Conversion of graphics into slides

Annals of Internal Medicine
154(2)
January 2011

Culturally Appropriate Storytelling to Improve Blood Pressure

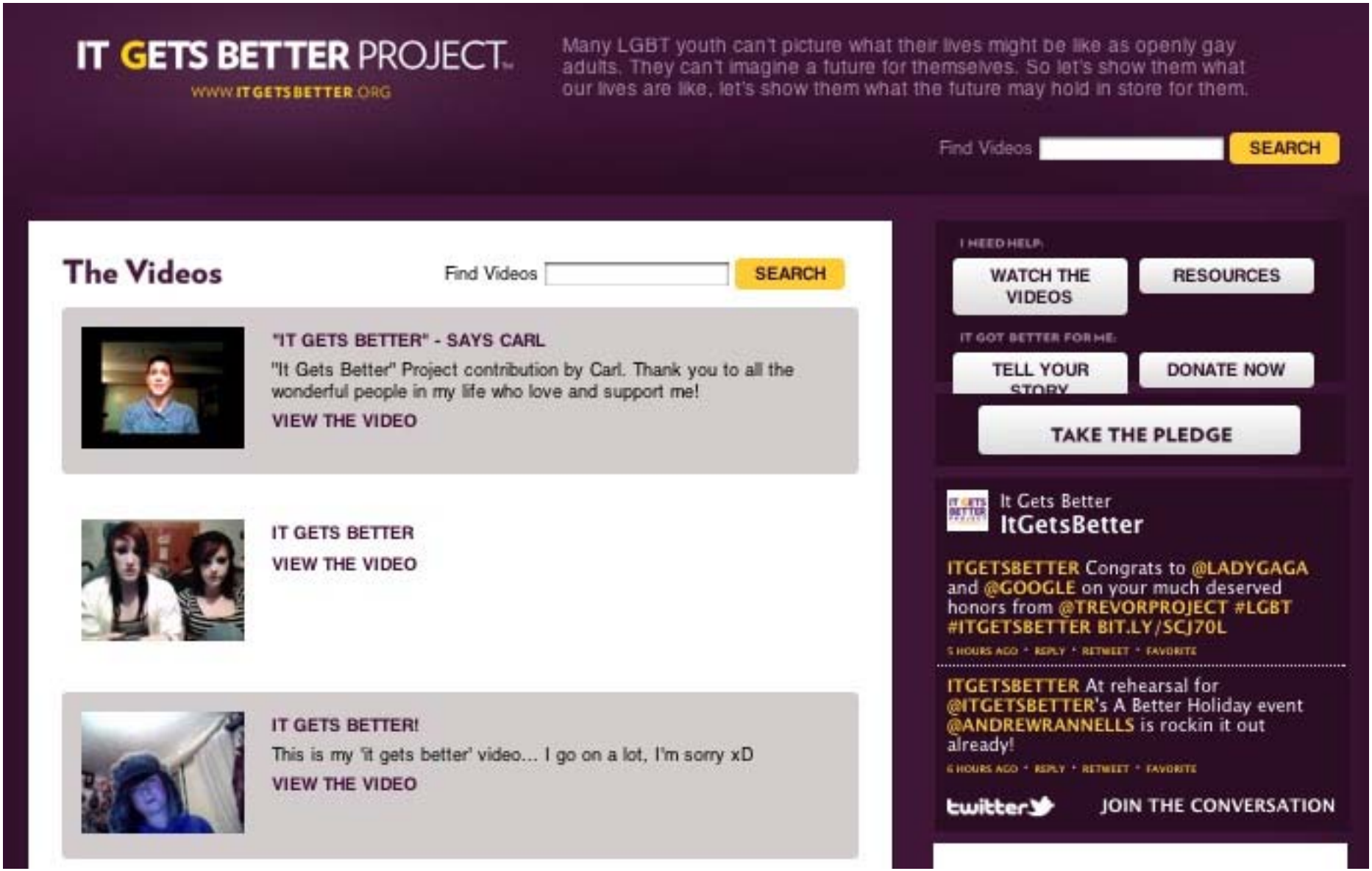
"We found that patients with uncontrolled hypertension who received a storytelling intervention with culturally sensitive messages that promoted hypertension control benefited from this intervention"

Example: Stats vs Story

- 75% of sexually active Canadians will have at least one HPV infection in their lifetime
- HPV affects about 550,000 Canadians every year and is one of the leading causes of cervical cancer in women
- 50 women die in BC every year from cervical cancer
- The highest rate of HPV infection is among young adults aged 15 to 24

Example: Stats vs Story

Storytelling in Other Health Campaigns



Storytelling in Other Health Campaigns

- The Anti-Vaccination Community
  - Jenny McCarthy and other parents
  - Innocent victims and concerned mothers

Breakout Exercise

Find Your Story!

Get Involved!

- How Can You Help?
  - Join our Mailing List (and enter to win an iPad!)
  - Like our Facebook Page
  - Tell Us Your Story!
- How Can I Have Immunity Help You?
  - Providing support and resources to help you communicate with anti-vax patients/community members
  - Providing tools and information about immunizations

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Thank You!

Join Our Campaign!

Discussion Q's

- How can we engage people in your health region/city/town/community?
- Challenges you foresee, based on your experience?
- Outreach ideas?