Storytelling to Motivate Change in Food Safety

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Washington, D.C. January 26, 2017

Center for Foodborne Illness Research & Prevention
Patricia Buck, Executive Director
Tell me the facts and I’ll learn. Tell me the truth and I’ll believe. But tell me a story and it will live in my heart forever.”

— an old Native American proverb
A Personal Story

Kevin Michael Kowalcyk, age 2 1/2
12/10/98 - 8/11/01
Kevin Kowalcyk
Victim of E. coli O157:H7 – Hemolytic Uremic Syndrome

Day 1-2: At home, vomit & diarrhea

Day 3: Bloody diarrhea – Went to ER and sent home – ER ordered stool testing

Day 4: Admitted to hospital and diagnosed with *E. coli* O157:H7

Day 5-11: Received 8 units of blood; was given multiple medications to control heart rate and blood pressure; had continuous dialysis; was placed on a respiratory ventilator; kept under sunlamps to stabilize his body temperature.

Day 12: 3 heart attacks. Died.
“Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.”

- Margaret Mead
Kevin’s Law, 2002-2008

- Introduced in the 107th, 108th and 109th Congresses.
- Had bi-partisan support, but was not passed.
- Kevin’s family led a campaign to get signatures on a petition.
- Kevin’s petition finally had 6,000 signatures from 36 states.
Kevin’s Story Raises National Awareness

Storytelling helps to accelerate social progress.
Storytelling and the Food Safety Modernization Act

Victim Advocates tell their stories
Foodborne Illness is a serious public health issue

Foodborne illness sickens 1 in 6
Which one will it be?

48 million illnesses
128,000 hospitalizations
3,000 deaths
And an undetermined number of long-term health problems
## More Than Just a Tummy Ache

<table>
<thead>
<tr>
<th>Select Long-term Health Outcomes (LTHOs) Associated with Foodborne Illness</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Autoimmune Disorders</strong></td>
</tr>
</tbody>
</table>
| **Reactive Arthritis** – associated with many foodborne pathogens; rates vary from 2.3% to 15%.  
**Guillain-Barre Syndrome** – *Campylobacter* is common trigger and accounts for 40% of cases in U.S. |
| **Digestive Disorders** |
| **Irritable Bowel Syndrome** – associated with many foodborne pathogens; causes estimated 17% of cases.  
**Irritable Bowel Disease** – includes Crohn’s Disease and Ulcerative Colitis. |
| **Neurological Disorders** |
| **Sepsis, Meningitis, Respiratory distress**  
**Paralysis, palsies, seizures, epilepsy**  
**Cognitive impairment, visual/hearing impairment** |
| **Renal Failure & Associated Sequelae** |
| **Hemolytic Uremic Syndrome (HUS)** – severe, life-threatening illness; leading cause of acute kidney failure in children under age 5 in U.S.; associated with STEC, *Shigella*.  
**Chronic kidney disease, End stage renal failure, Chronic hypertension, Pancreatitis, Diabetes mellitus** – often secondary to HUS. |
| **Emerging Issues** |
| **Schizophrenia, psycho-social disorders** – recent studies have found increased risk for toxoplasmosis but not well understood. |
Long-Term Health Outcome Story: Autoimmune Disorders

Reactive arthritis

- Painful, swollen joints.
- Greatly affects quality of life.
- *Salmonella* leading predictor.
- Rates vary from 2.3% to 15%.

*Dana -- Salmonella*
LTHO Story: Digestive Disorders

- **Irritable Bowel Syndrome (IBS)**
  - Affects ~12% globally.
  - 2.4-3.5M doctor visits/yr
  - Costs $30 billion / year
  - Associated with E. coli, Yersinia, Salmonella, Campylobacter and Shigella.
  - Causes ~17% of IBS.

- **Irritable Bowel Disease (IBD)**
  - Crohn’s Disease
  - Ulcerative Colitis

*Tammy, Salmonella*
LTHO Story: Hemolytic Uremic Syndrome

- Leading cause of acute kidney failure in children under age 5 in U.S.
- Acute illness is serious
- Long-term outcomes serious:
  - Renal dysfunction
  - Hypertension
  - Diabetes
  - Cardiovascular disease
  - Neurological dysfunction
- Associated with all STECs and Shigella.

Ashley, E. coli O157:H7
LTHO Story: Neurological Disorders

- Severe sepsis, meningitis, respiratory distress
- Visual, hearing impairment
- Paralysis, palsies
- Seizures, epilepsy
- Cognitive impairment
- Psychosocial
- Listeriosis - 20% long-term impairment
- Toxoplasmosis – 80% show impairment by age 17

Mariah, E. coli O157:H7
More work needs to be done

### FOOD SAFETY PROGRESS REPORT FOR 2013

<table>
<thead>
<tr>
<th>Disease Agents</th>
<th>Percentage change in 2013 compared with 2006–2008</th>
<th>2013 rate per 100,000 Population</th>
<th>2020 target rate per 100,000 Population</th>
<th>CDC estimates that...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Campylobacter</td>
<td>13% increase</td>
<td>13.82</td>
<td>8.5</td>
<td>For every Campylobacter case reported, there are 30 cases not diagnosed</td>
</tr>
<tr>
<td><em>Escherichia coli</em> O157</td>
<td>No change</td>
<td>1.15</td>
<td>0.6</td>
<td>For every <em>E. coli</em> O157 case reported, there are 26 cases not diagnosed</td>
</tr>
<tr>
<td>Listeria</td>
<td>No change</td>
<td>0.26</td>
<td>0.2</td>
<td>For every Listeria case reported, there are 2 cases not diagnosed</td>
</tr>
<tr>
<td>Salmonella</td>
<td>No change</td>
<td>15.19</td>
<td>11.4</td>
<td>For every Salmonella case reported, there are 29 cases not diagnosed</td>
</tr>
<tr>
<td>Vibrio</td>
<td>75% increase</td>
<td>0.51</td>
<td>0.2</td>
<td>For every <em>Vibrio parahaemolyticus</em> case reported, there are 142 cases not diagnosed</td>
</tr>
<tr>
<td>Yersinia</td>
<td>No change</td>
<td>0.36</td>
<td>0.3</td>
<td>For every Yersinia case reported, there are 123 cases not diagnosed</td>
</tr>
</tbody>
</table>

For more information, see [http://www.cdc.gov/foodnet/](http://www.cdc.gov/foodnet/)

Preliminary FoodNet 2013 Data

April 2014
Food safety challenges moving forward

How Multi-Drug Resistance (MDR) Develops

- Lots of germs – only a few drug resistant ones
- Antibiotics kill all bacteria, including good bacteria
- Without any competition, MDR strains take over
- Other bacteria receive traits from MDR strains

WHO and CDC agree that MDR bacteria is a major public health threat in the 21st century.
Challenges:

- Low appreciation of the seriousness of foodborne diseases or the development of long-term health outcomes.

- Without appreciation of the risk, there is low motivation to adopt a new behavior.
Remembering Why It Is Important

Abby
Died, Age 7
*E. coli* O157:H7

Ruby
Died, Age 81
*E. coli* O157:H7

Kevin
Died, Age 2
*E. coli* O157:H7

Kayla
Died, Age 14
*E. coli* O157:H7

Dana
Salmonella

Ashley
*E. coli* O157:H7

Mariah
*E. coli* O157:H7

John
Salmonella
Questions?

Thank You!

buck@foodborneillness.org

www.foodborneillness.org

See below for additional resources.

- Guiseppe Arcimboldo
Some Story Resources

For CFI victim stories (Kevin, Ashley and Polly):
http://www.foodborneillness.org/videos.html

Videos in the public domain:

https://mail.google.com/mail/u/0/#search/food+safety+videos/1598f345d01a5274?projector=1 (Rylee’s story with HUS from eating spinach)

https://www.youtube.com/watch?v=7Nut_dNl-x4 (Dana’s story, cantaloupe)

https://www.youtube.com/watch?v=5ASFXImyeLE (Bernadette’s story, sandwich)

https://www.youtube.com/watch?v=K0hRrkn21E4 (Kevin’s story, ground meat)
Higher Risk for Vulnerable Populations

Long-Term Health Outcomes Report, 2009

Young Children and Foodborne Illness Fact Sheet, 2014