TELLING YOUR STORY: COMMUNICATING AND ADVOCATING FOR SCIENCE IN CHALLENGING TIMES
HOW DO WE COMMUNICATE ABOUT SCIENCE?

Infectious Diseases/Human Immunodeficiency Virus Physician Ambassadors: Advancing Policy to Improve Health

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Infectious diseases/human immunodeficiency virus (IDHIV) physicians and other healthcare professionals advocate within the healthcare system to ensure adults and children receive effective treatment. These advocacy skills can be used to inform domestic and global infectious diseases policies to improve healthcare systems and public health. IDHIV physicians have a unique frontline perspective to share with federal policymakers regarding how programs and policies benefit patients and public health. Providing this input is critical to the enactment of legislation that will maximize the response to infectious diseases. This article discusses the advocacy of IDHIV physicians and other healthcare professionals in federal health policy. Key issues include funding for IDHIV programs; the protection of public health and access to healthcare; improving research opportunities; and advancing the field of IDHIV, including supporting the next generation of IDHIV clinicians. The article also describes best practices for advocacy and provides case studies illustrating the impact of IDHIV physician advocacy.

Keywords: infectious diseases; HIV; physician advocacy.
HOW DO WE COMMUNICATE ABOUT SCIENCE?
HOW OFTEN DO YOU CURRENTLY TALK ABOUT SCIENCE TO NON-SCIENTISTS?

- Daily?
- Weekly?
- Monthly?
- Can’t remember the last time?
WHY SHOULD YOU? WHY DON’T WE?

- Science misinformation is abundant
- Creating “doubt” is easier when fewer Americans have broad scientific knowledge
- Consequences can be dire
JAMES LIND (1716-1794)

• Planned a comparative trial of several popular scurvy cures during a long voyage
  – 12 men with scurvy ate a common diet, slept together
    • 2 men given a quart of cider daily
    • 2 men given an elixir
    • 2 men given seawater
    • 2 men given horseradish/mustard/garlic
    • 2 men given vinegar
    • 2 men given oranges and lemons
• Published in 1753
• British ships did not supply citrus to ships until 1795
THE SURFACTANT STORY . . .

• 1929: Animal models showed that lowering surface tension could be useful for improving respiration
  – Follow up studies in 1940s-1950s showed similar results
  – 1950s: human autopsy studies show increased surface tension associated poor respiratory outcomes and death

• 1963: President Kennedy’s son dies “hyaline membrane disease”

• 1960s: First clinical trials fail
  – Pulmonary ischemia rather than surfactant deficiency?

• 1972: Back to animal model – surfactants effective in rabbits
“VALLEY OF DEATH”

- Drug discovery (1975): $138 million
- Drug discovery (2005): $1 billion
  - Over 45% of that cost attributable to clinical trials
- Scientific journals publish over 1 million papers annually
  - 396 potential drugs submitted to FDA

https://www.nature.com/articles/453840a
"I’m a fiction writer in the grant-proposal genre."
COSTUMES TO SCARE SCIENTISTS

I STILL NEED A GANTT CHART!

A GRANT PROPOSAL DUE TOMORROW

YOU CAN'T CATCH ME!

UNACCOUNTED-FOR VARIABLE

IT'S ME YOUR THESIS!

THE UNFINISHED MANUSCRIPT

YOU SHOULD BE ASHAMED.

REVIEWER 2

I'M INSIGNIFICANT.

P > 0.1

THEY KNOW!

YOUR IMPOSTER SYNDROME MADE FLESH!

@twisteddoodles
HOW DOES THE VACCINE WORK?

- mRNA: Blueprint or work instructions telling our cells how to make a protein (Spike protein)

- Antibody to Spike protein prevents viral entry

Explaining The Science Behind An mRNA Vaccine For COVID-19: 1A: NPR
'Redemption': How a scientist's unwavering belief in mRNA gave the world a Covid-19 vaccine (telegraph.co.uk)
Vaccine Hesitancy

Ten threats to global health in 2019

Thanks to Paul Darden for slide
IT HASN’T ALWAYS BEEN THIS WAY . . .

Parents of Earth, are your children fully immunized?

Make sure—call your doctor or health department today, and may the force be with you.

Star Wars PSA
# Impact of Vaccines in the 20th & 21st Centuries

<table>
<thead>
<tr>
<th>Disease</th>
<th>Pre-Vaccine Est. Cases/Year</th>
<th>Cases Reported in 2010</th>
<th>Percent Decrease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diphtheria</td>
<td>21,053</td>
<td>0</td>
<td>100%</td>
</tr>
<tr>
<td>Tetanus</td>
<td>580</td>
<td>8</td>
<td>99%</td>
</tr>
<tr>
<td>Pertussis</td>
<td>200,752</td>
<td>21,291</td>
<td>89%</td>
</tr>
<tr>
<td>Measles</td>
<td>530,217</td>
<td>61</td>
<td>&gt;99%</td>
</tr>
<tr>
<td>Mumps</td>
<td>162,344</td>
<td>2,528</td>
<td>98%</td>
</tr>
<tr>
<td>Rubella</td>
<td>47,745</td>
<td>6</td>
<td>&gt;99%</td>
</tr>
<tr>
<td>Chickenpox</td>
<td>&gt;4 million</td>
<td>449,363</td>
<td>89%</td>
</tr>
<tr>
<td>Rotavirus</td>
<td>62,500</td>
<td>7,500</td>
<td>88%</td>
</tr>
</tbody>
</table>

Use of Merck's Vaccine Surges During Measles Scare

As news of a California measles outbreak spread in January, health officials urged parents to vaccinate their children. The surge boosted Merck's sales of its measles and other vaccines 24 percent last quarter.

California finds seven measles cases. By February, more than 100 would be infected.

Use of Merck's vaccine peaks at more than four times normal rates.

As news spreads, use of Merck's vaccine rises.

Source: Data compiled by Bloomberg

The moment we want to believe something, we suddenly see all the arguments for it, and become blind to the arguments against it.

(George Bernard Shaw)
Effective Messages in Vaccine Promotion: A Randomized Trial; Nyhan, et al, *Pediatrics*

**FIGURE 2**
Predicted intervention effects for MMR intention. The figure depicts predicted probabilities and bootstrapped 95% confidence intervals from the ordered logit models in Table 3 generated using SPost in Stata 11. The panel presents the predicted probability that respondents would answer "Very likely" to the question "If you had another child, how likely is it that you would give that child the measles, mumps, and rubella vaccine, which is known as the MMR vaccine?" for respondents with the least favorable attitudes toward vaccines, those with somewhat favorable attitudes, and those with the most favorable attitudes (the groups were defined based on a tercile split of responses to the vaccine attitudes scale from Freed et al, which was administered in a previous wave of the study). Corrective information disproving the vaccine/autism link reduced intent to vaccinate among parents with the least favorable attitudes toward vaccines; no significant effect was found among the other groups. Intervention text is provided in the Supplemental Information.
“Abstract data and facts related to health impacts can be difficult to interpret for non-scientific audiences especially when missing the human element of the story. Ultimately, people care about how research impacts the real world and their daily life.

Communicating those impacts with storytelling doesn’t take away from the seriousness or quality of our research but enhances it for a broader audience. It also helps increase digital engagement and create opportunities for content sharing with collaborators.”

-PALLAVI PANT, Senior Scientist, the Health Effects Institute
Trust Me, I'm a Scientist

Why so many people choose not to believe what scientists say

By Daniel T. Willingham on May 1, 2011
“ANY SCIENTIST WHO CAN’T EXPLAIN TO AN EIGHT-YEAR-OLD WHAT HE IS DOING IS A CHARLATAN.”

KURT VONNEGUT
Science communication

scientists

the public
Define goals of communications

WHAT

Identify the needs of your particular audience

WHO

Create & disseminate messages tailored to intended audience

HOW

Don’t assume you know their needs!

Partner with your community of interest!
WHAT’S THE “HOW”? 

- Start with the most important point
  - Describe the process afterwards
  - Focus on the bigger impact

- Keep it simple
  - Always competing & overlapping communication goals
  - Choose your purposeful, focused goal for this audience
  - Communicate it over a cup of coffee or at a dinner party
  - Avoid jargon

- Use examples & illustrations
  - Actual illustrations or stories

- Keep it relatable
  - Conversational
  - “The minute I started thinking of the general public as “other,” I compromised my ability to be an effective communicator.”
    - Katherine Wu, May 2017, Scientific American
AND, BUT, THEREFORE

- Background statement 1
  AND
- Background statement 2
- BUT statement 3
- THEREFORE statement 4

- Obesity killed my mother and is killing the rest of us with rising health care costs and decreasing expected life span
- And we have proven strategies that help people lose weight.
- But they aren’t easy for a busy health provider in a community clinic to initiate.
- Therefore, we are developing ways to help primary care providers in small and large towns better stem the tide of obesity and its health effects.

Randy Olson, Don’t be such a scientist
15% chance someone in any group of 25 people is COVID-19 positive
CNS SHUNTS

- Treatment of hydrocephalus
  - Establishment of a pathway for drainage that by-passes the ventricular drainage system.
  - Cannulation of the ventricle without causing hemorrhage or other injury.
- 18,000 CNS shunts placed per year
  - $100 million
IL-10 PLAYS A SIGNIFICANT ROLE IN REGULATING INFLAMMATORY RESPONSE

Gutierrez-Murgas, et al, 2015, J Neuroinflammation
IL-10 was also detectable in CSF following infection.

In press, Skar, et al.
And it shows up in human CSF as a factor that might differentiate Gram-positive vs Gram-negative infections

Skar, et al, J Neuroinflammation 2019
SO WHAT COMES NEXT?

- Clinical research
  - Observational studies to confirm that biomarker is similar in humans?
  - Interventional trial to test use of biomarker to direct therapy?
NEW TOOLS TO PROTECT GROWING BRAINS

- Understanding how the brain “sees” infection may help us protect growing brains
  - Especially important in children with hydrocephalus
  - IL-10 turns off inflammation in the brain to protect it from damage & may be something we can use to improve treatment
IT TAKES PRACTICE . . .
How often SHOULD you talk about science to non-scientists?
EVERY DAY

Sir Mark Walport, U.K. Government Chief Scientific Adviser
RESOURCES

- Alda Center @aldacenter
- Home • Science Communication Project • Iowa State University (iastate.edu)
- Associations/Research Groups//Blogs and Websites - Science Communication - Guides at Penn Libraries (upenn.edu)
- AAAS Home | American Association for the Advancement of Science
  - AAAS Communication Toolkit | American Association for the Advancement of Science
  - Communication Fundamentals | American Association for the Advancement of Science (aaas.org)
- [10 Tips for Effective Science Communication | Northeastern University](http://www.neu.edu/)
- Why Can't Scientists Talk Like Regular Humans? - Scientific American Blog Network
- The 3 Essential Rules For Effective Science Communication (forbes.com)
- The narrative truth about scientific misinformation | PNAS
- Randy Olson Great Challenges Day at TEDMED 2013 - YouTube
RESOURCES FOR ETHICAL STORYTELLING

- Donor Travel Resources (philanthropywithoutborders.com)
- 7 ways to tell stories ethically: the journey from exploited program participant to empowered storyteller - CCF (communitycentricfundraising.org)
- 5 Ways for Nonprofits to Tell an Ethical Story - Non Profit News | Nonprofit Quarterly
- How to Tell Compelling Stories While Avoiding Savior Complex and Exploitation - RVC (rvcseattle.org)
Play “Just the Vax” Vaccine Trivia Game

“Vaccine Trivia: Just the Vax” is the Vaccine Education Center’s trivia game. As part of the Parents PACK program, the vaccine trivia game offers a fun way to learn about vaccines. It includes four categories of questions about vaccines from which to choose: historical/famous figures, safety, vaccines and vaccine-preventable diseases.
VACCINE MAKERS PROJECT
Curriculum for Elementary, Middle & High School

Videos & Animations | The Vaccine Makers Project