



**TELLING YOUR
STORY:
COMMUNICATING
AND ADVOCATING
FOR SCIENCE IN
CHALLENGING
TIMES**

JESSICA SNOWDEN

JSNOWDEN@UAMS.EDU

HOW DO WE COMMUNICATE ABOUT SCIENCE?



Clinical Infectious Diseases

MAJOR ARTICLE



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

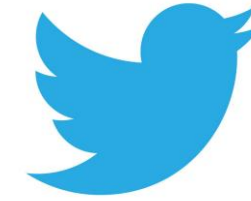
Maximo O. Brito,^{1,2} Caitlin M. Dugdale,^{3,4} Michelle Collins-Ogle,⁵ Jessica Snowden,⁶ and David A. Wheeler^{7,8}

¹Division of Infectious Diseases, Department of Medicine, University of Illinois at Chicago, Chicago, Illinois, USA, ²Jesse Brown VA Medical Center, Chicago, Illinois, USA, ³Division of Infectious Diseases, Massachusetts General Hospital, Boston, Massachusetts, USA, ⁴Harvard Medical School, Boston, Massachusetts, USA, ⁵Pediatric Infectious Diseases, Children's Hospital at Montefiore, Einstein College of Medicine, Bronx, New York, USA, ⁶Division of Pediatric Infectious Disease, University of Arkansas for Medical Sciences, College of Medicine, Department of Pediatrics, Little Rock, Arkansas, USA, ⁷Infectious Diseases Physicians, Inc, Annandale, Virginia, USA, and ⁸Virginia Commonwealth University, Division of Infectious Diseases, Inova Fairfax Medical Campus, Annandale, Virginia, USA

Infectious diseases/human immunodeficiency virus (ID/HIV) 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. ID/HIV 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 ID/HIV physicians and other healthcare professionals in federal health policy. Key issues include funding for ID/HIV programs; the protection of public health and access to healthcare; improving research opportunities; and advancing the field of ID/HIV, including supporting the next generation of ID/HIV clinicians. The article also describes best practices for advocacy and provides case studies illustrating the impact of ID/HIV physician advocacy.

Keywords. infectious diseases; HIV; physician advocacy.

HOW DO WE COMMUNICATE ABOUT SCIENCE?





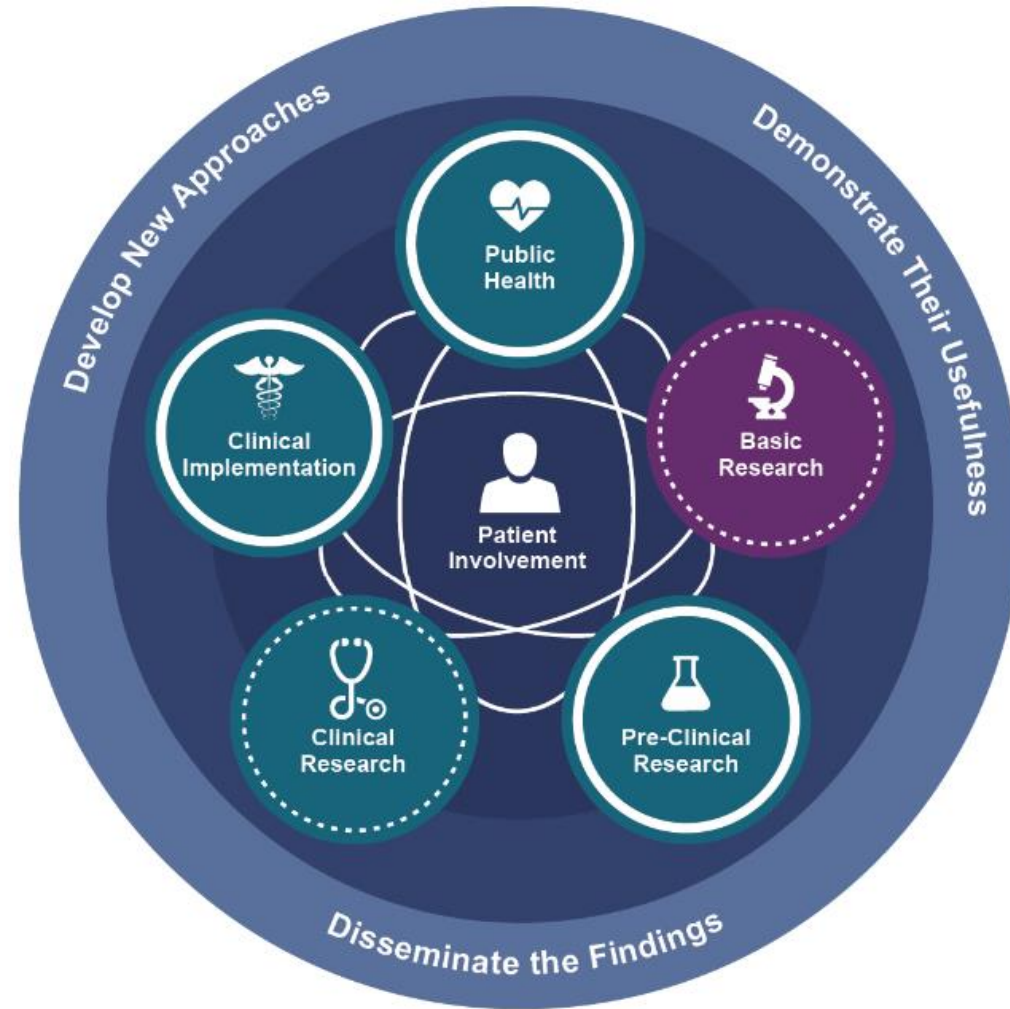
HOW OFTEN DO YOU CURRENTLY TALK ABOUT SCIENCE TO NON-SCIENTISTS?

- 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



ncats.nih.gov

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 . . .

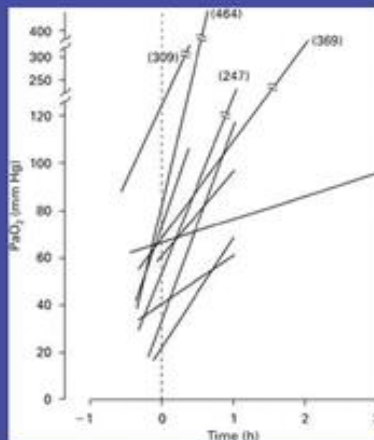
- 1929: Animal models showed that lowering surface tension could be useful for improving respiration
 - Follow up studies in 1940s-1950s showed similar results
 - 1950s: human autopsy studies show increased surface tension associated poor respiratory outcomes and death
- 1963: President Kennedy's son dies "hyaline membrane disease"
- 1960s: First clinical trials fail
 - Pulmonary ischemia rather than surfactant deficiency?
- 1972: Back to animal model – surfactants effective in rabbits



Tetsuro Fujiwara
1931 –

- Surfactant TA
- 10 infants
- 30 wk; >1500 g
- 9 had PDA
- 2 died

1. Worked in Adams' laboratory in Los Angeles, California in the 1960s and the 1970s
2. Returned to Japan and treated ten preterm babies with a modified natural surfactant (Surfactant-TA)

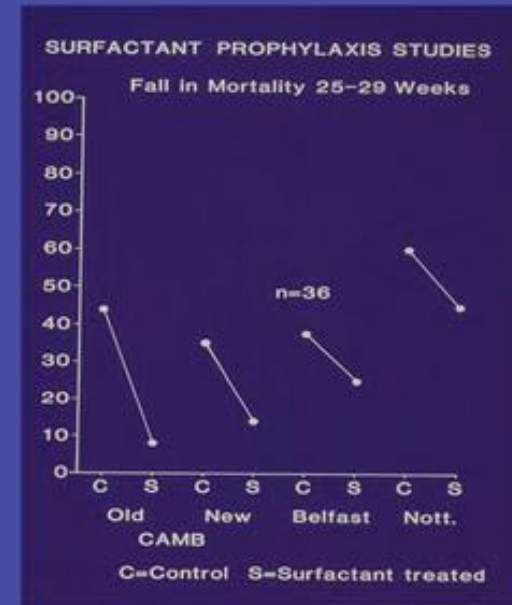


Fujiwara et al: Lancet 1980; i:55-59

Colin Morley



Pumactant or ALEC with Alec Bangham in 1980s – DPPC and PG.
Halliday et al: Lancet; i: 476-8: Turfsurf – DPPC and HDL.



UK trials with DPPC-based surfactants

Collaborative European Multicenter Study Group. Surfactant replacement therapy for severe neonatal respiratory distress syndrome: An international randomized clinical trial. *Pediatrics* 1988; **82**: 683–91.

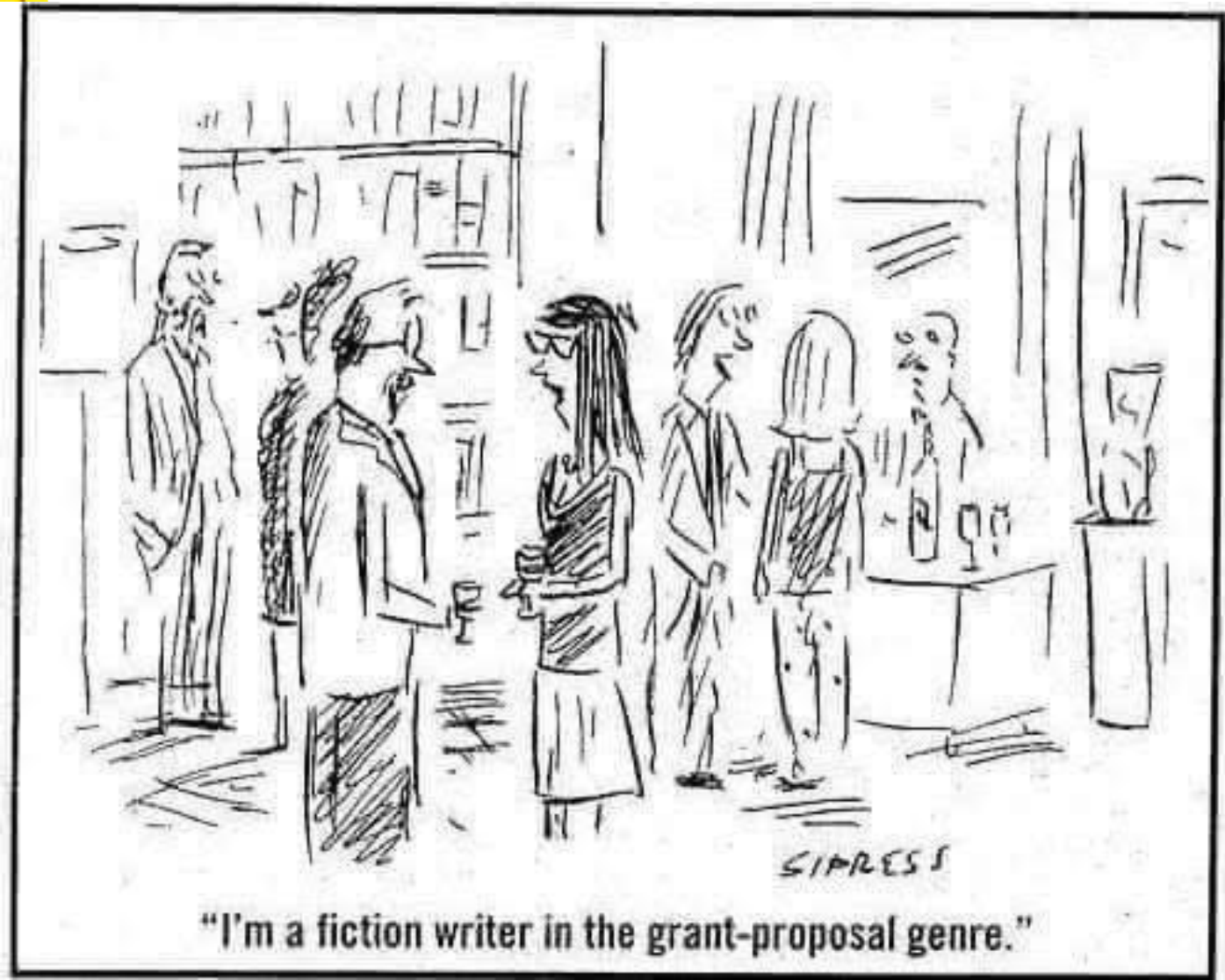
“VALLEY OF DEATH”

- Drug discovery (1975): \$138 million
- Drug discover (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



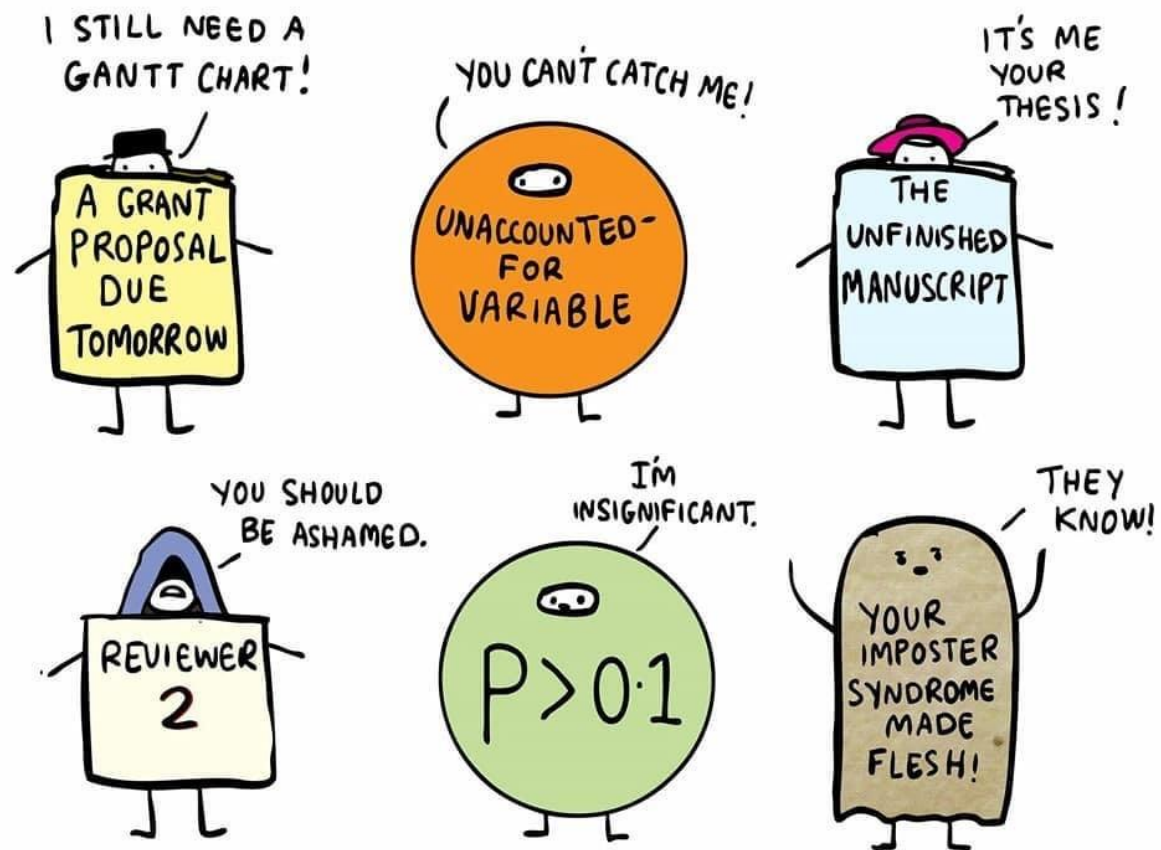
<https://www.nature.com/articles/453840a>



SIAPRES

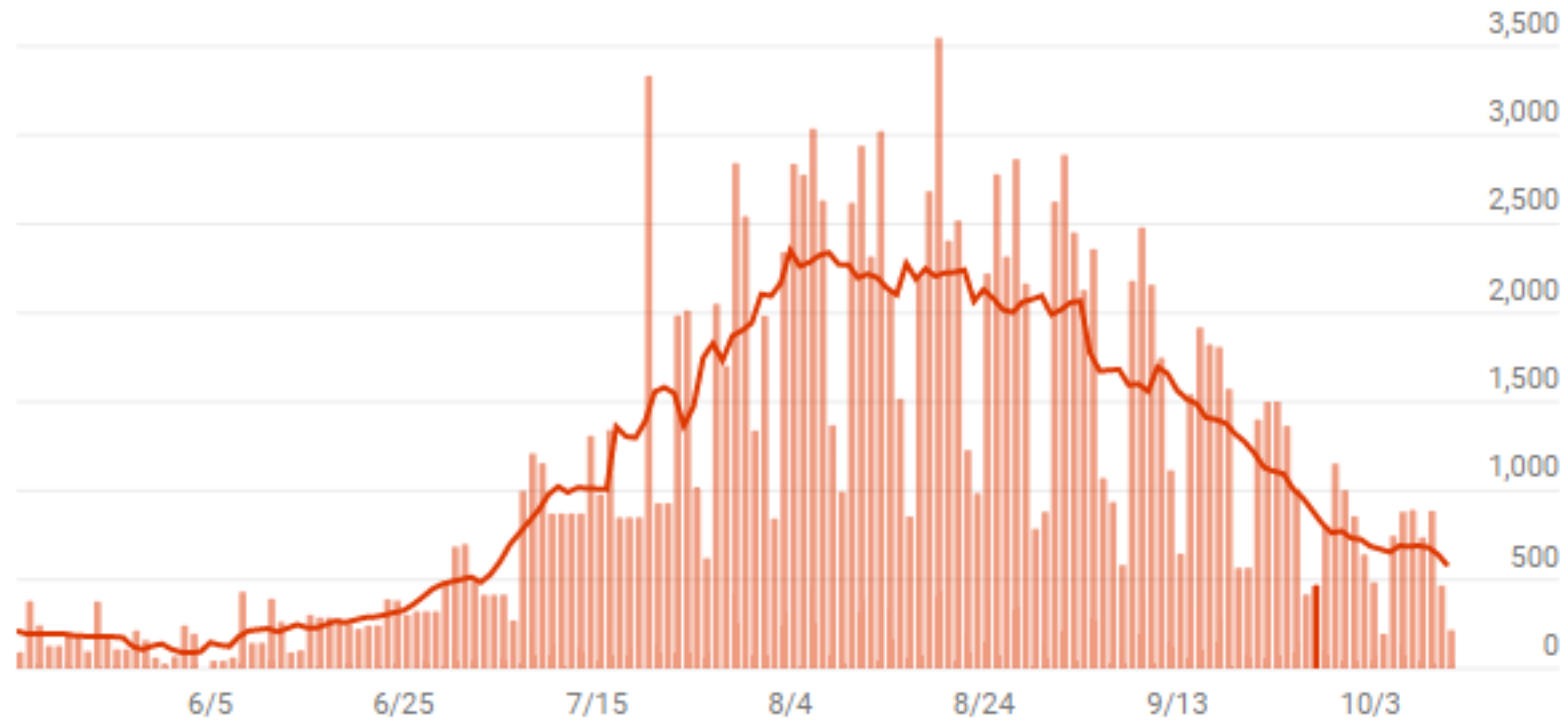
"I'm a fiction writer in the grant-proposal genre."

COSTUMES TO SCARE SCIENTISTS

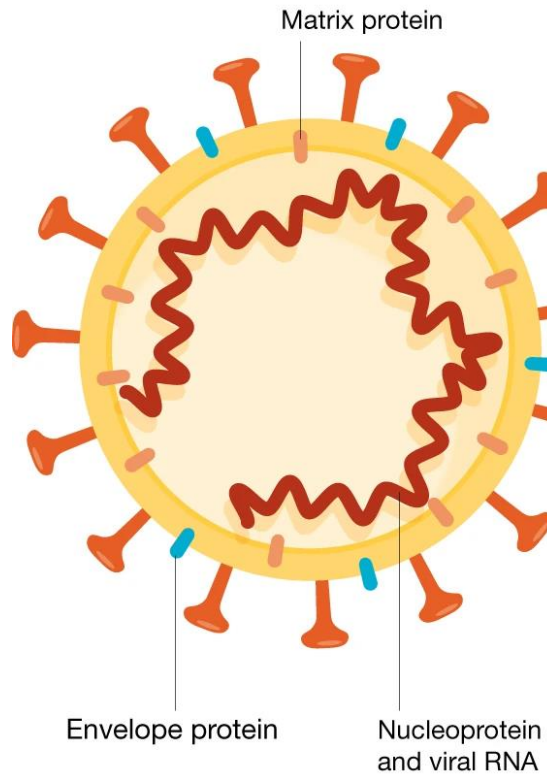


@twisteddoodles

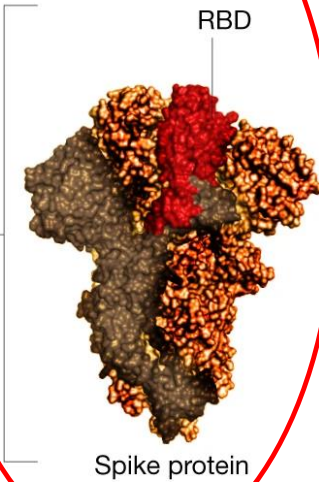
Daily new cases



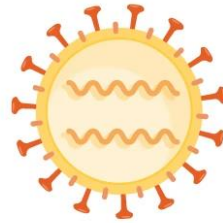
a SARS-CoV-2



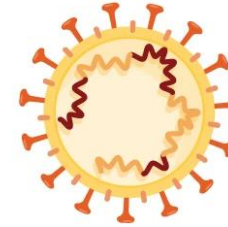
b RBD of the spike protein



c Inactivated vaccines contain SARS-CoV-2 that is grown in cell culture and then chemically inactivated



d Live attenuated vaccines are made of genetically weakened versions of SARS-CoV-2 that is grown in cell culture



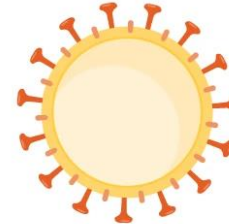
e Recombinant spike-protein-based vaccines



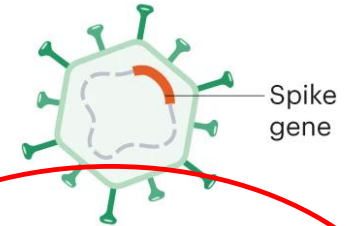
f Recombinant RBD-based vaccines



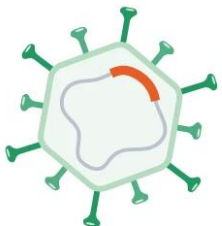
g VLPs carry no genome but display the spike protein on their surface



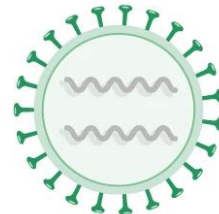
h Replication-incompetent vector vaccines cannot propagate in the cells of the vaccinated individual but express the spike protein within them



i Replication-competent vector vaccines can propagate to some extent in the cells of the vaccinated individual and express the spike protein within them



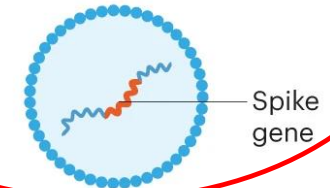
j Inactivated virus vector vaccines carry copies of the spike protein on their surface but have been chemically inactivated



k DNA vaccines consist of plasmid DNA encoding the spike gene under a mammalian promoter

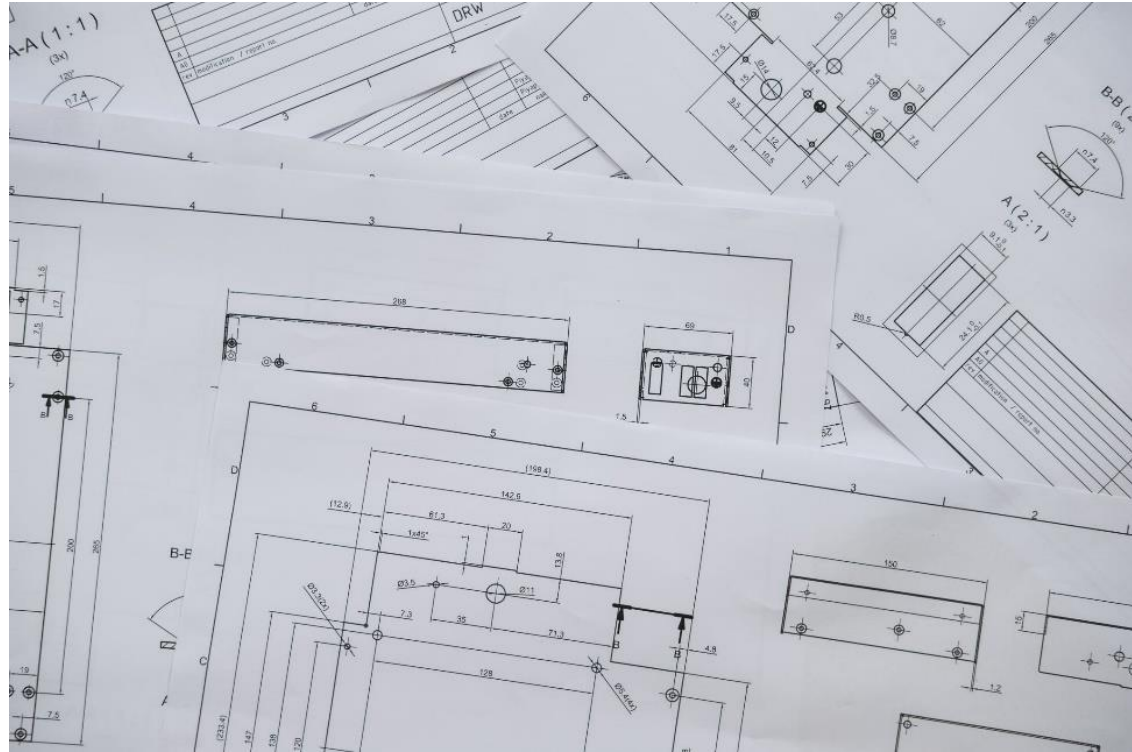


l RNA vaccines consist of RNA encoding the spike protein and are typically packaged in LNPs



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](#)



Katalin Karikó

['Redemption': How a scientist's unwavering belief in mRNA gave the world a Covid-19 vaccine](#)
[\(telegraph.co.uk\)](https://www.telegraph.co.uk)



Vaccine Hesitancy

Ten threats to global health in 2019

IT HASN'T ALWAYS BEEN THIS WAY . . .



Star Wars PSA

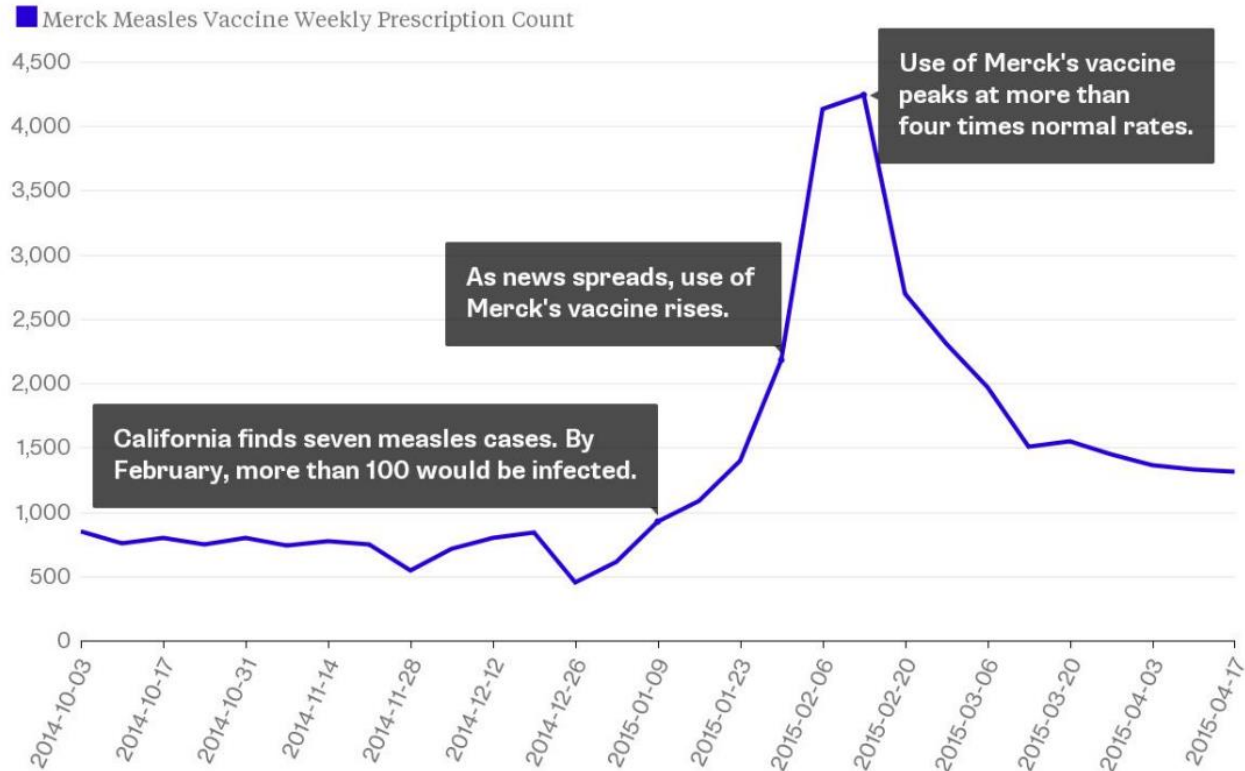
IMPACT OF VACCINES IN THE 20TH & 21ST CENTURIES

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

Source: Epidemiology and Prevention of Vaccine-Preventable Diseases, 12th Edition, May, 2011, p G7.

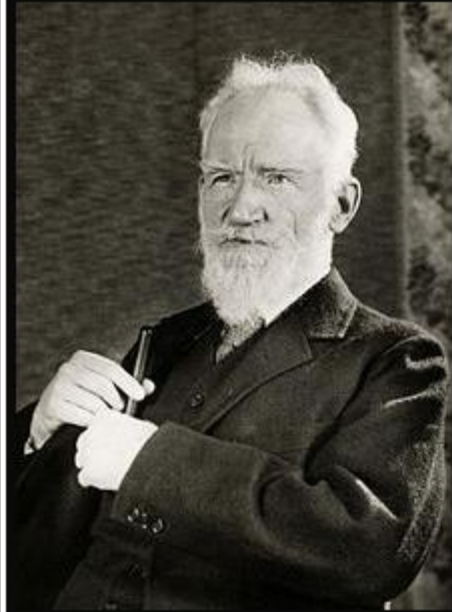
Use of Merck's Vaccine Surges During Measles Scare

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.



Source: Data compiled by Bloomberg

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)

IZQuotes

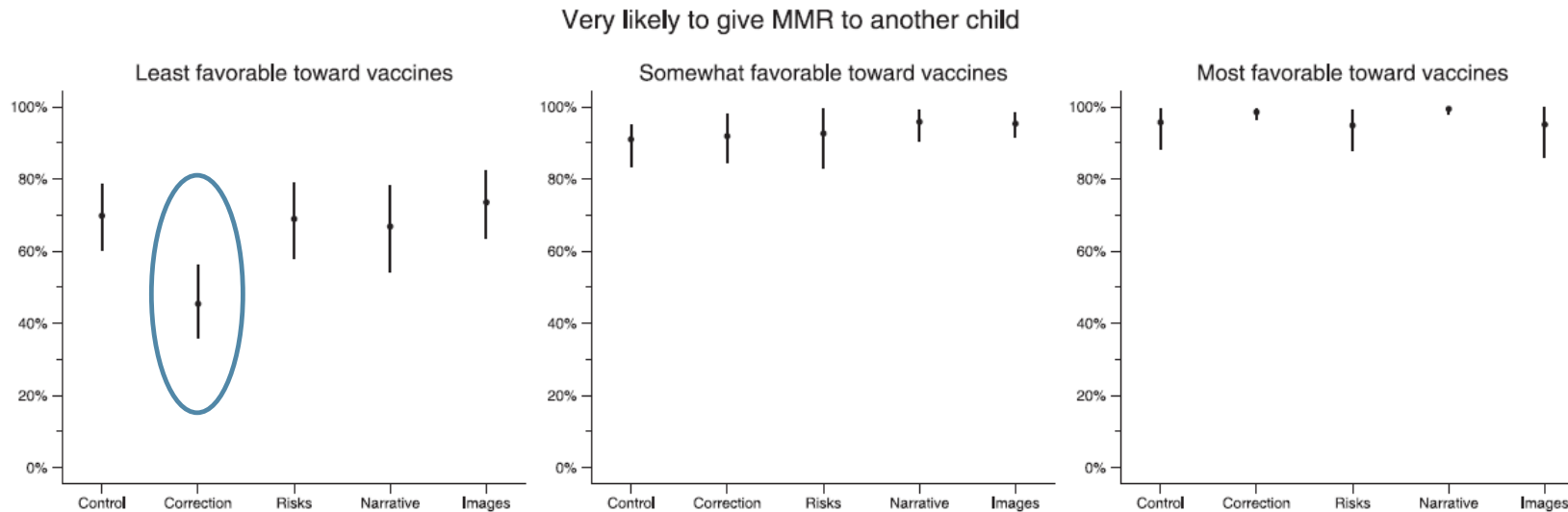


FIGURE 2

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 11.⁴⁶ 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

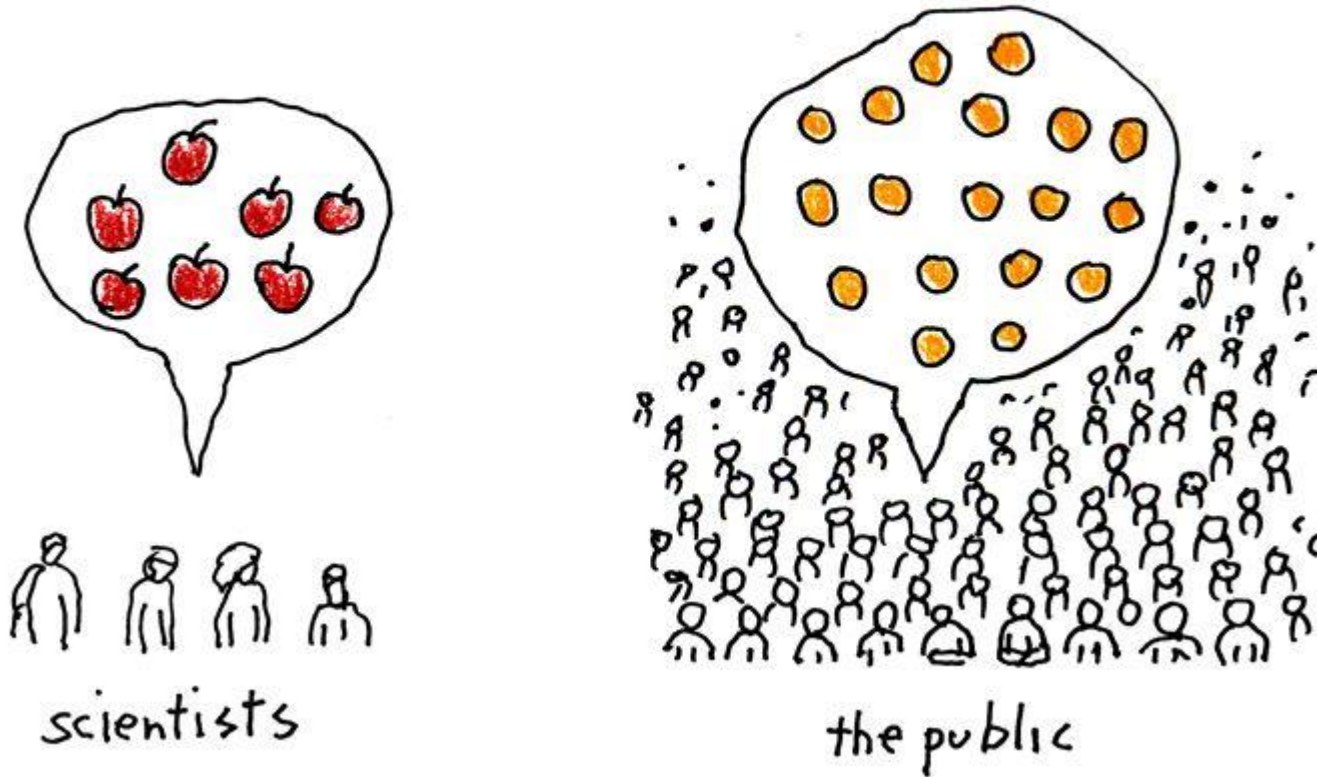
By Daniel T. Willingham on May 1, 2011

***“ANY SCIENTIST WHO CAN’T EXPLAIN TO AN EIGHT-YEAR-
OLD WHAT HE IS DOING IS A CHARLATAN.”***

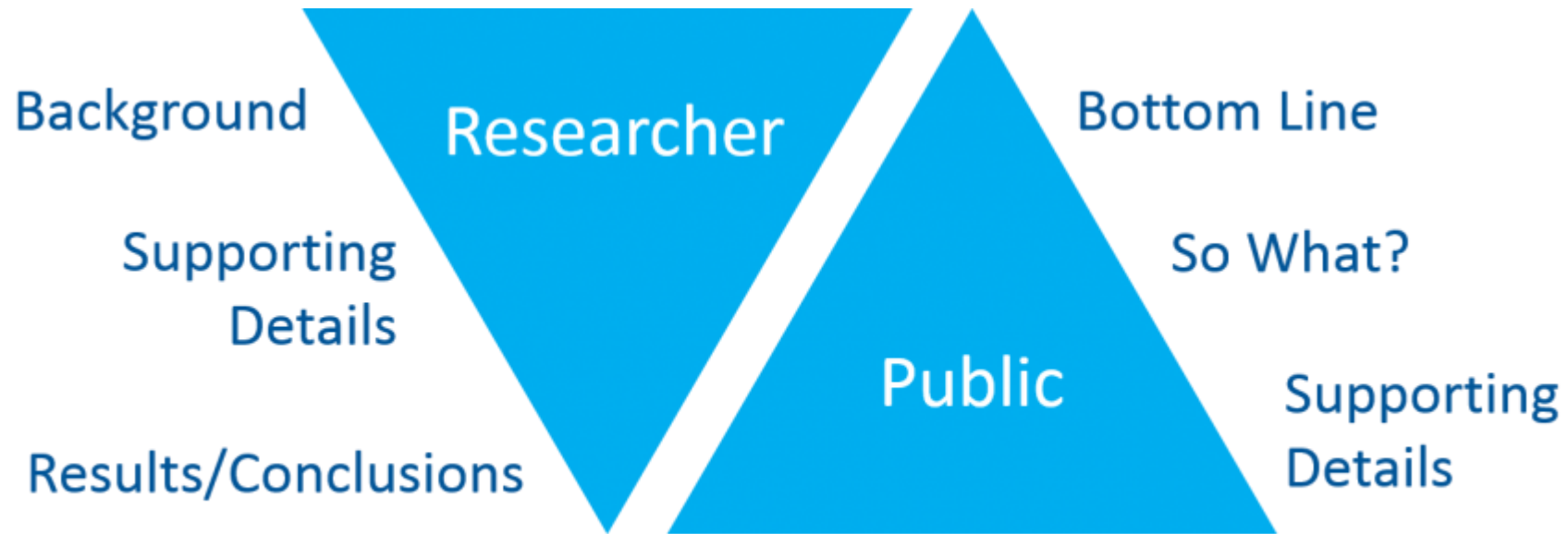
KURT VONNEGUT



Science communication



FLIP THE SCRIPT



WHAT

Define goals of communications

Don't assume you know their needs!



Identify the needs of your particular audience

WHO

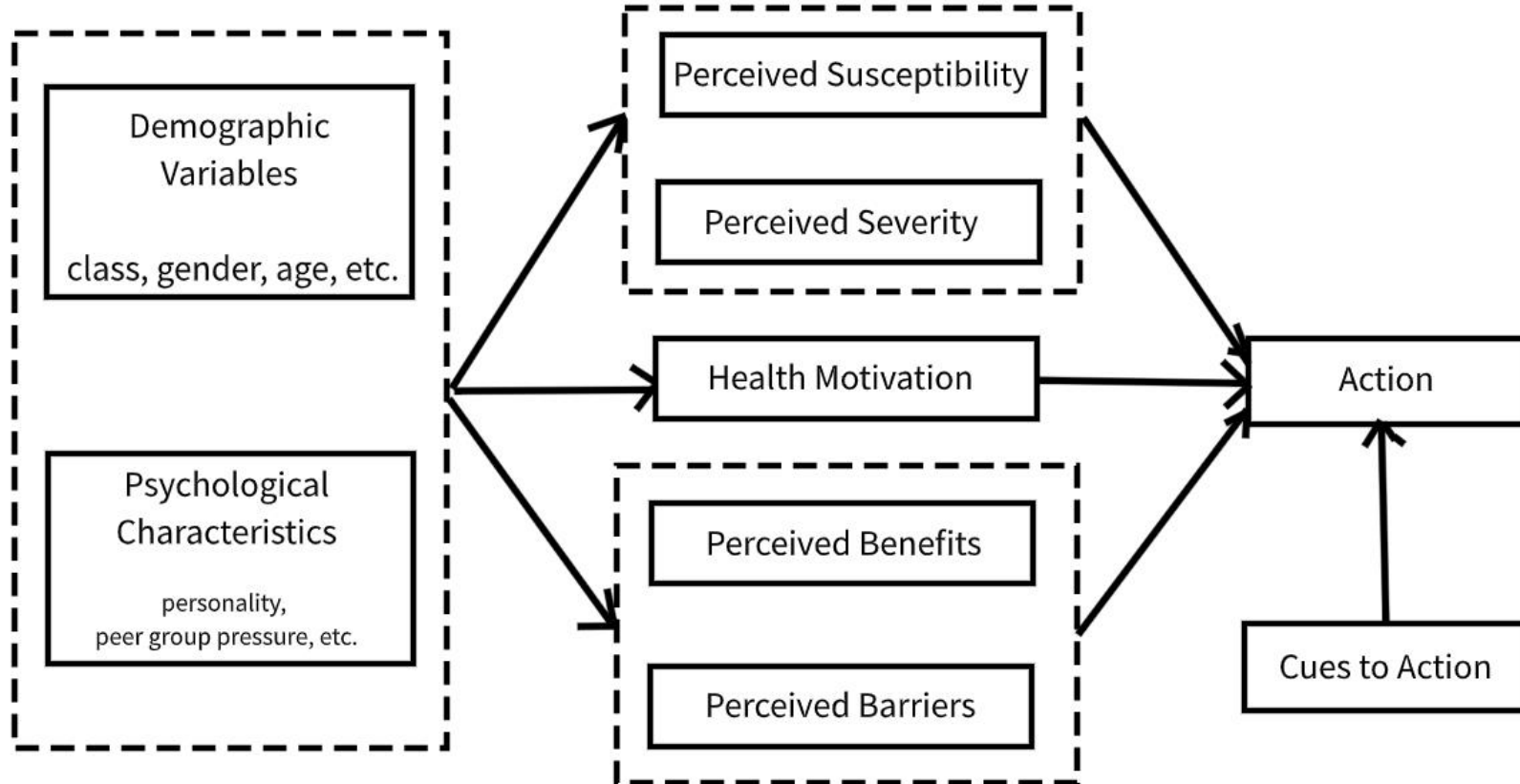
HOW

Create & disseminate messages tailored to intended audience



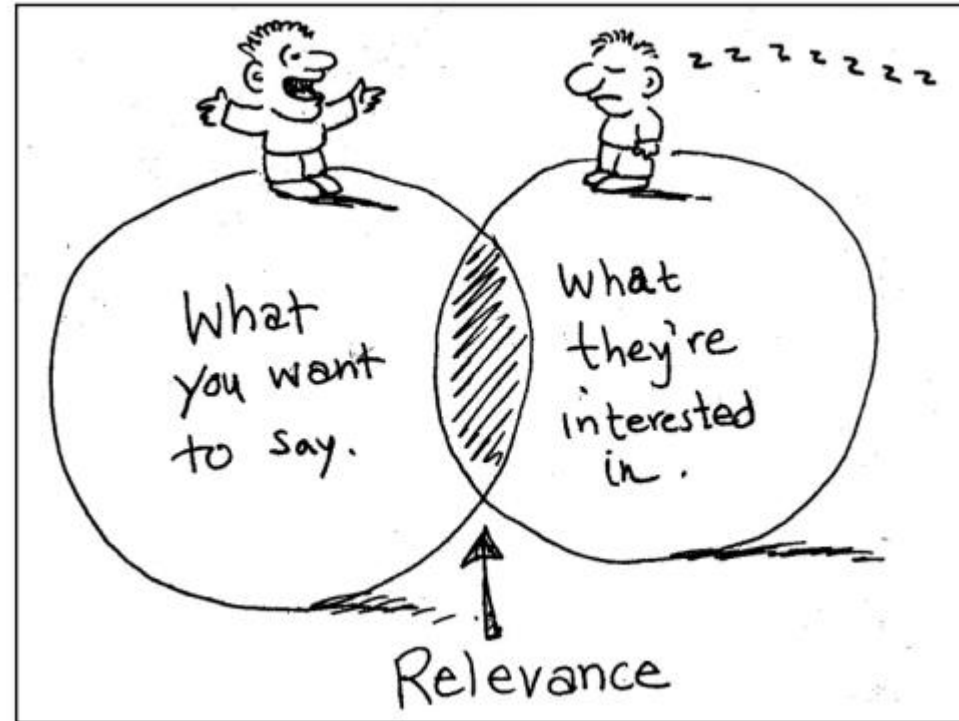
Partner with your community of interest!

The Health Belief Model



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, THEREFOROE

- 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.

RISK CONTEXT

×

You're viewing risk levels for an event with 25 people, which is like:

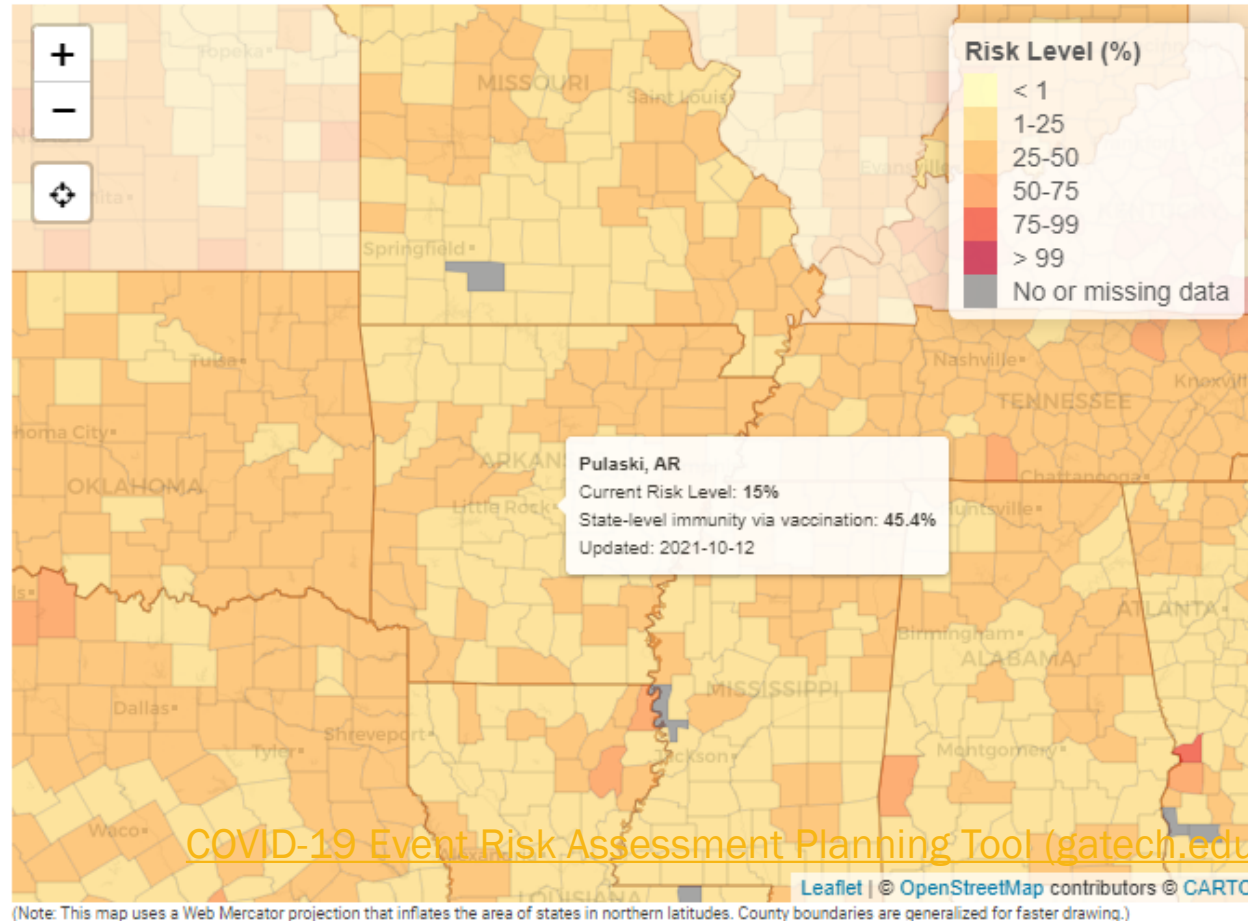
A classroom



...or small bar



Can you
guess the

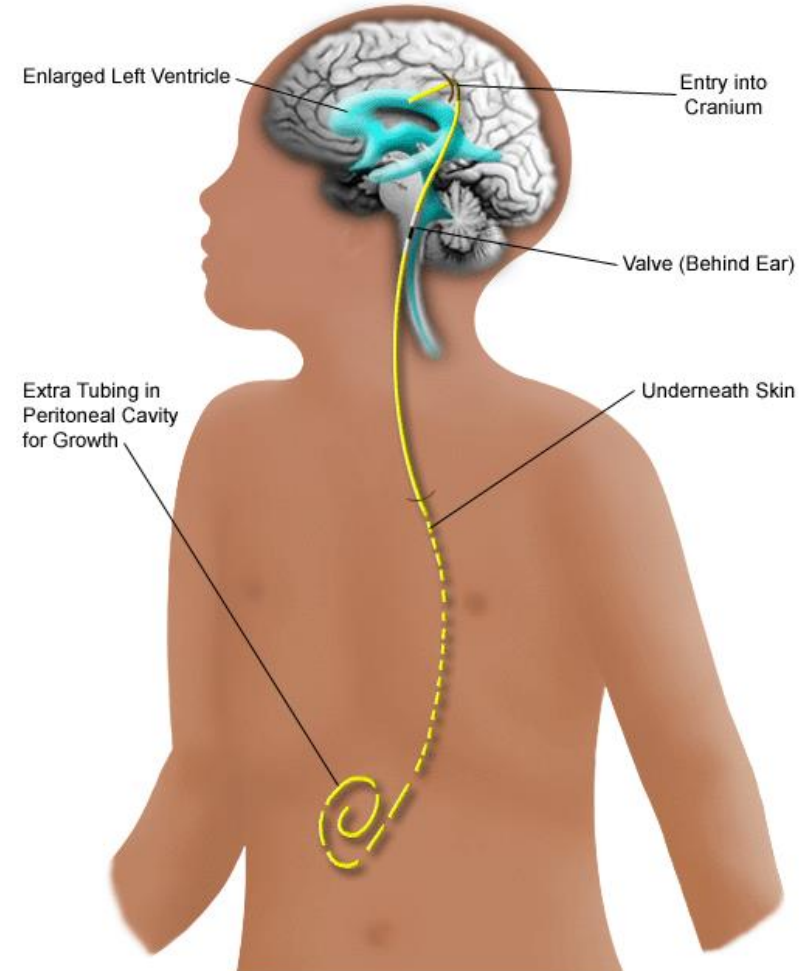


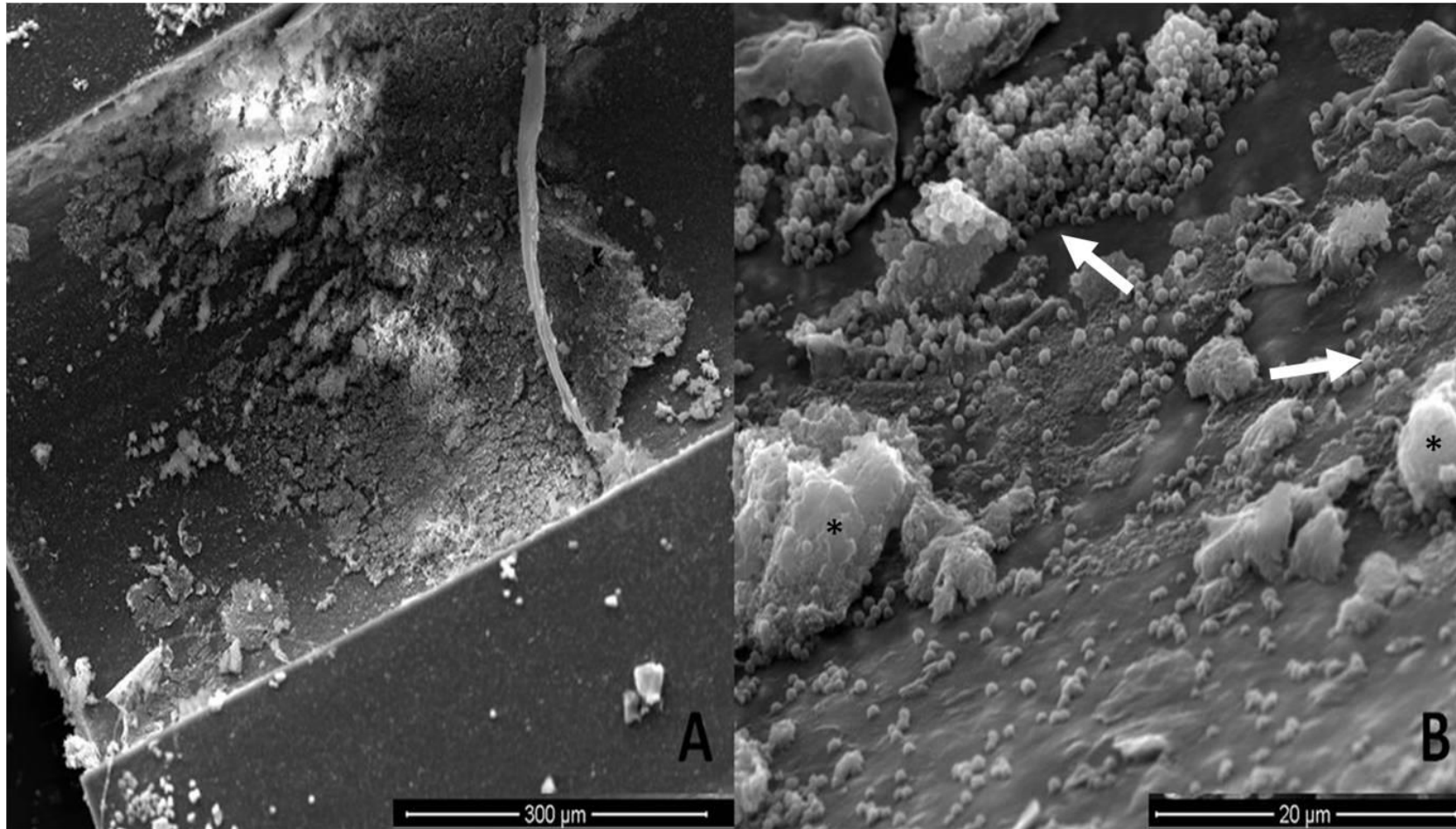
15% chance
someone in any
group of 25
people is COVID-
19 positive

CNS SHUNTS

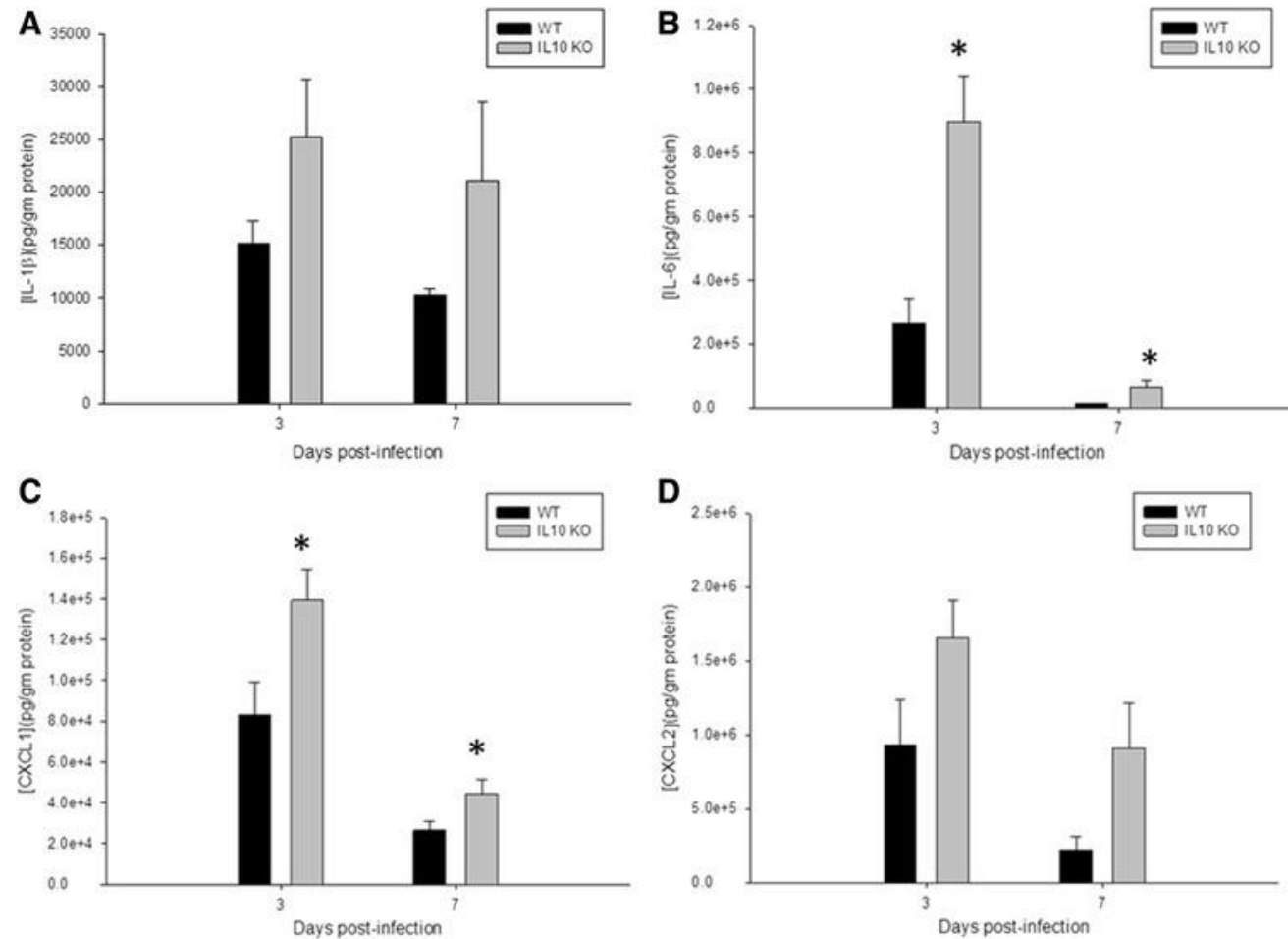
- Treatment of hydrocephalus
 - Establishment of a pathway for drainage that by-passes the ventricular drainage system.
 - Cannulation of the ventricle without causing hemorrhage or other injury.
- 18,000 CNS shunts placed per year
 - \$100 million

Ventriculoperitoneal Shunt Placement

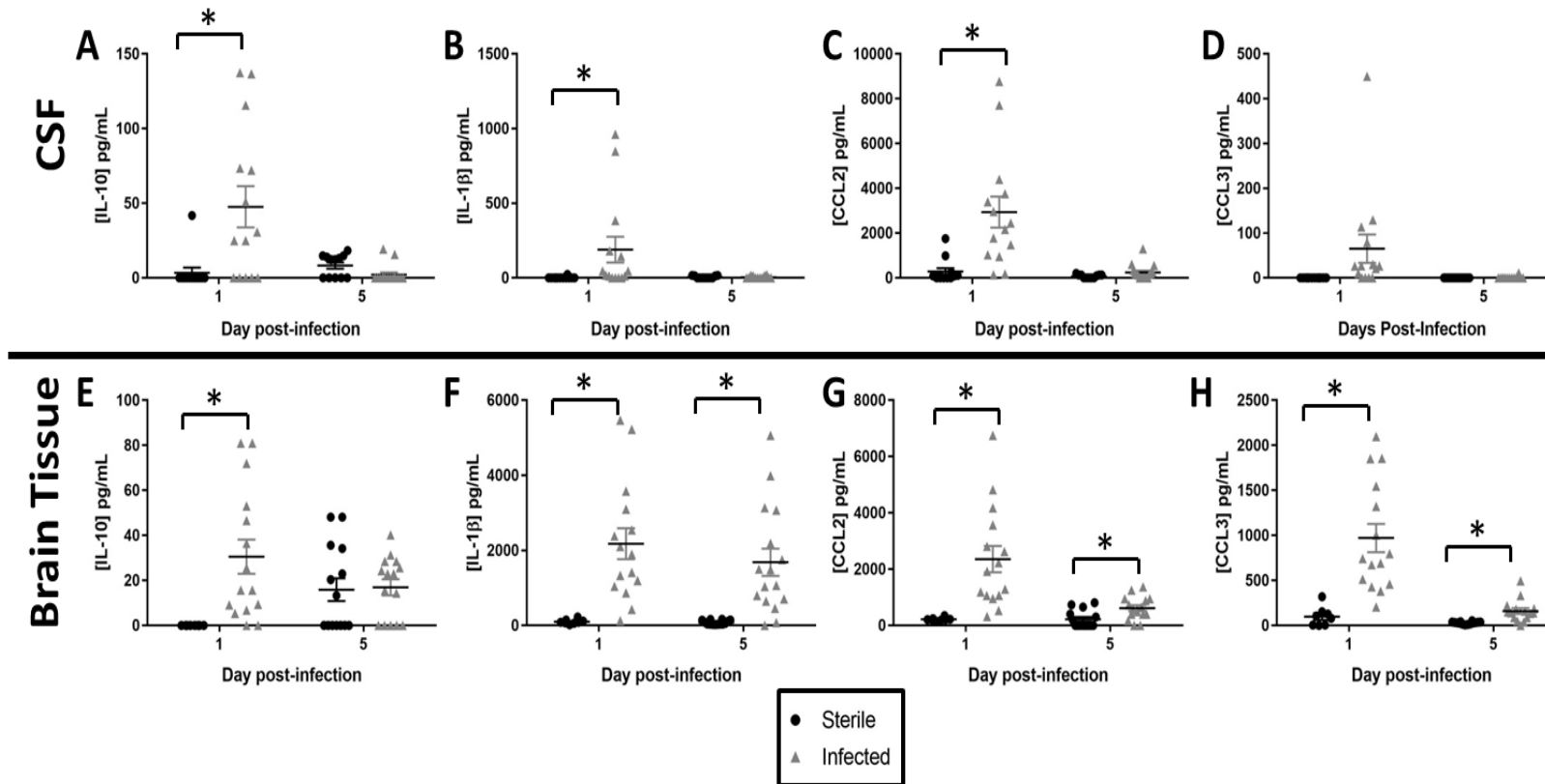




IL-10 PLAYS A SIGNIFICANT ROLE IN REGULATING INFLAMMATORY RESPONSE

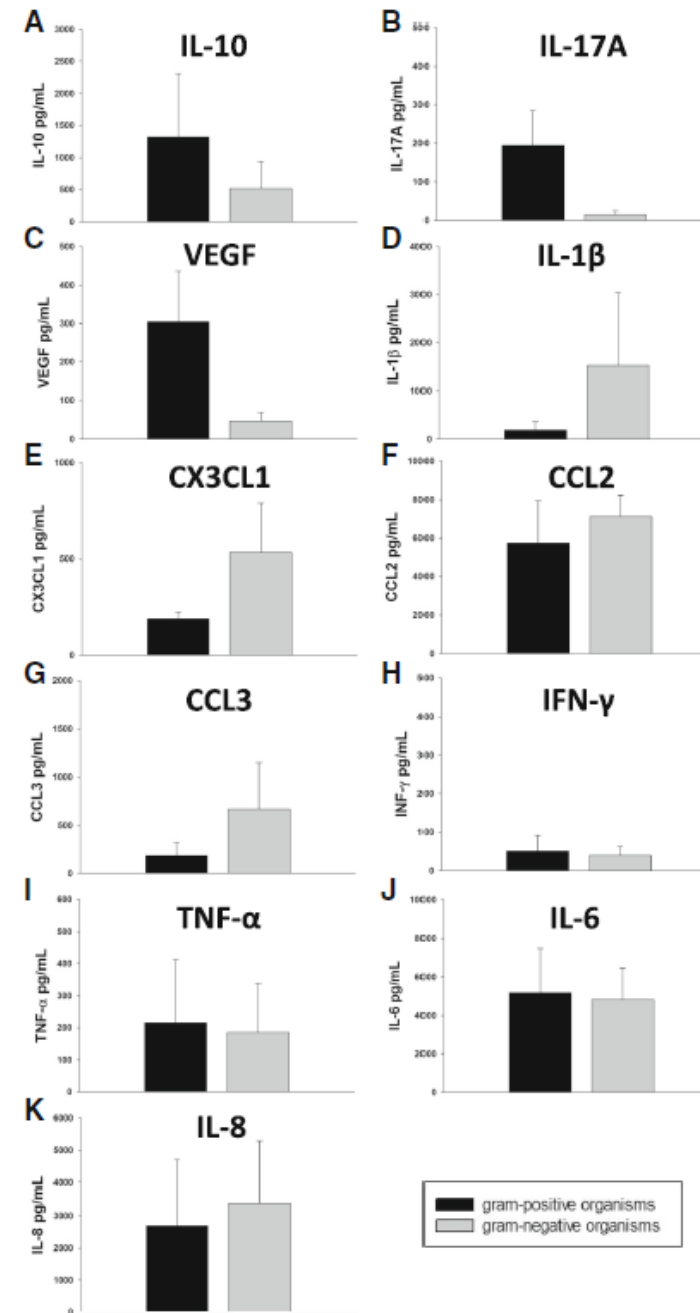


IL-10 WAS ALSO DETECTABLE IN CSF FOLLOWING INFECTION



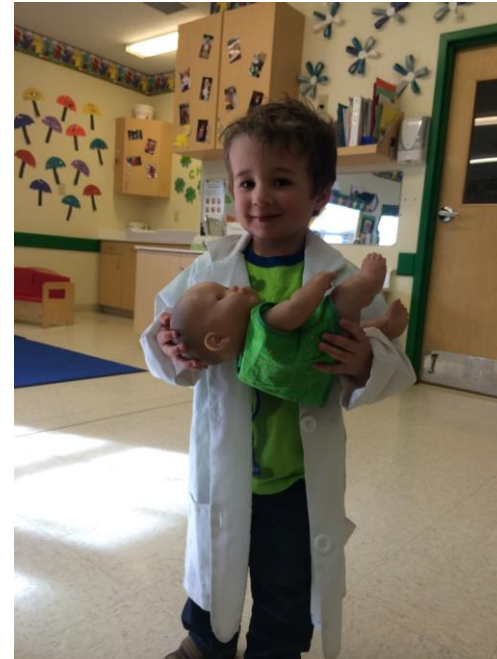
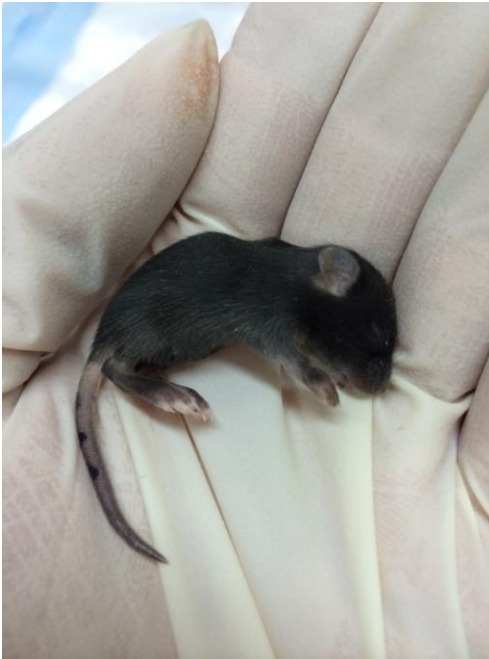
In press, Skar, et al.

And it shows up in human CSF as a factor that might differentiate Gram-positive vs Gram-negative infections



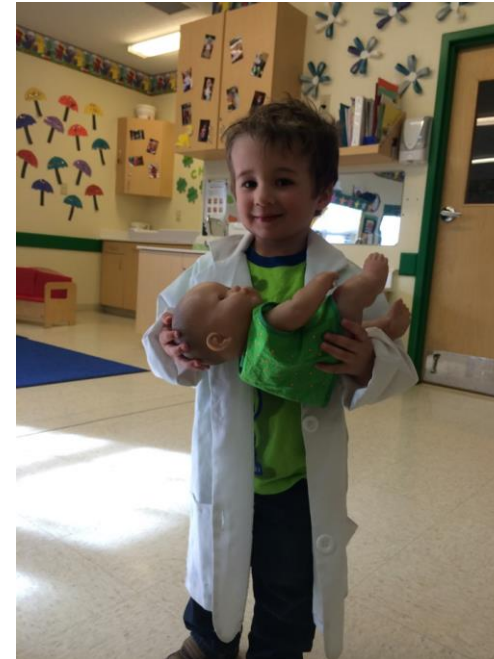
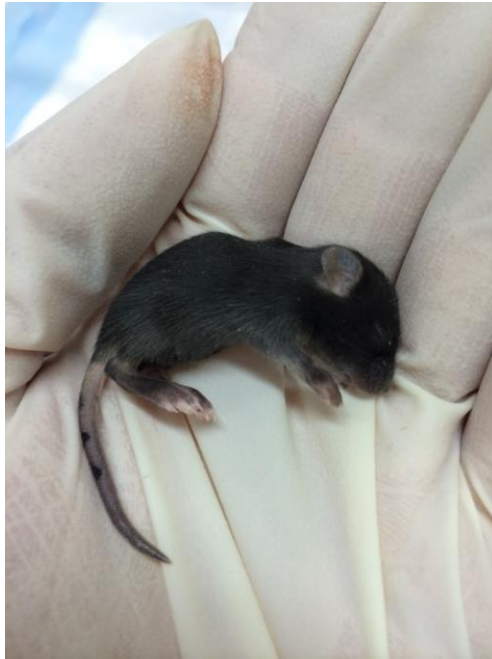
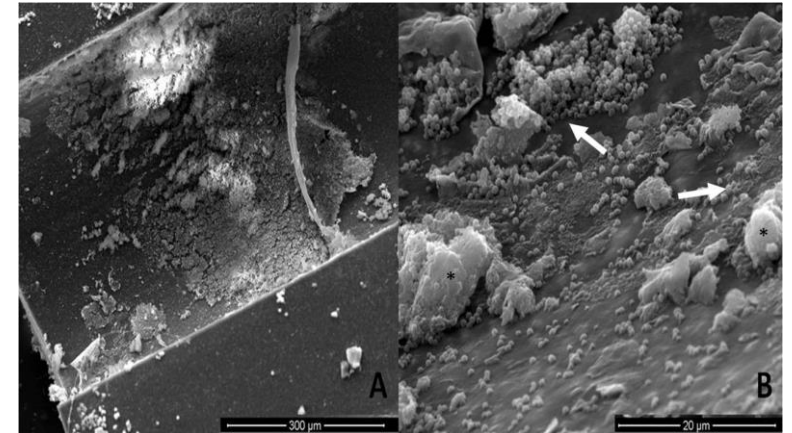
SO WHAT COMES NEXT?

- 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 . . .



A close-up photograph of a silver mesh microphone on the right side of the frame. The background is dark with out-of-focus, colorful bokeh lights in shades of purple, pink, and yellow. At the top of the image, there are three horizontal bars: a grey one on the left, a blue one in the middle, and a grey one on the right.

**SCIENCE ISN'T FINISHED UNTIL IT IS
COMMUNICATED.**

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
- Science Communication: A Practical Guide from MIT <http://ocw.mit.edu/courses/science-technology-and-society/sts-034-science-communication-a-practical-guide-fall-2011/Syllabus/>
- [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](#)
- [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 \(philanthropywithoutborders.com\)](https://philanthropywithoutborders.com)
- [7 ways to tell stories ethically: the journey from exploited program participant to empowered storyteller - CCF \(communitycentricfundraising.org\)](https://communitycentricfundraising.org)
- [5 Ways for Nonprofits to Tell an Ethical Story - Non Profit News | Nonprofit Quarterly](https://nonprofitquarterly.com)
- [How to Tell Compelling Stories While Avoiding Savior Complex and Exploitation - RVC \(rvcseattle.org\)](https://rvcseattle.org)

VACCINE EDUCATION CENTER

- Family & community fact sheets
- Sample presentations

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](#)

A Virus Attacks a Cell (Animation)

