

Visual Storytelling in ELSI Research

April 14, 2023 at 12pm ET/9am PT



**Elizabeth Gross Cohn,
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City University of New York,
Columbia University



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Moderated by
Sara Ackerman, PhD, MPH
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Do you see what I see?
ELSI and Photovoice

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ELSI Friday Forum Seminar Series
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Thank you for allowing us to share this work:

National Institutes of Health

- Center to Improve Chronic disease Outcomes through Multi-level and Multi-generational approaches Unifying Novel Interventions and Training for health Equity (The COMMUNITY Center) NIMHD 5P50MD017341-02 Terry, PI.
- The Interdisciplinary Guided Network for Investigation, Translation and Equity. NIH OT2 OD031915 Cohn, PI.
- Center for Research on Ethical, Legal & Social Implications of Psychiatric, Neurologic & Behavioral Genetics NIH 5RM1HG007257-09 Appelbaum, PI.

Columbia University:

- Mellon Foundation: The Trust Collaboratory at Columbia University.

I'll share two projects, one successful and less so, for your discussion and critique.

ELSI Issues are fundamentally based on trust, understanding, and communication

Guided by the National Human Genome Research Institute's the Partnership for Community Outreach and Engagement is committed to:

- Building relationships and trust with communities through understanding diverse communal views and priorities.
- Providing input and guidance on the development of programs, tools, and information for various communities.
- Providing community perspectives about genomic research and science.
- Identifying potential areas of collaboration between communities, NHGRI and other National Institutes of Health (NIH) institutes, and national and international organizations.

Photovoice is one tool to help us achieve some of those goals.

- Photovoice is a process in which people use video and/or photo images to capture aspects of their environment and experiences and share them with others. The pictures can then be used, usually with captions composed by the photographers, to bring the realities of the photographers' lives home to the public and policy makers and to spur change.
- Based on work developed by Caroline Wang and Mary Ann Burris (1992), Photovoice is based on a combination of Paulo Freire's concept of "critical consciousness" (a deep understanding of the way the world works and how society, politics, and power relationships affect one's own situation); feminist theory, which emphasizes the importance of voice; and documentary photography, which is often used to help bring about social change.
- Wang and Burris gave cameras to a group of rural village women in Yunnan Province in China, who documented their lives and environment for an entire year. Groups of women gathered at regular intervals to view and discuss the pictures they took. At the end of the project, the group hosted an exhibition of their photographs, and used it to raise the consciousness of the general public and of policy makers about their needs. The women had gained a voice, greater self-respect, and a sense of increased control over their lives.

How to study Trust?



- Trust is one of the defining issues of our time. It is the invisible and yet it is the core and the anchor of our most intimate relationships.
- Trust is vital in shaping how citizens interact with public institutions, scientific knowledge, medical expertise, hospitals, and doctors. During the pandemic, we have heard a lot about a mistrust—in science, in medicine, in vaccines, in government.
- What and who makes it possible for us to trust?
- We begin a conversation about *Trust Workers*: those who build trust, and who can help restore it.

- We invite you to take a tour of the photovoice stories of Community Health Workers (CHWs)—the pandemic’s unsung heroes and society’s *Trust Workers*, for whom trust is written into their job description. Our exhibit explores three main themes: What is trust in the eyes of CHWs, who are trusted in their communities and whose everyday work depends on it? How do CHWs obtain and repair trust when it is absent or lost? And how do CHWs use trust to improve the health of the communities they serve and represent?

**A PHOTOVOICE
EXHIBITION**

PREMIERE IN MANHATTANVILLE 2022
CURRENTLY TOURING NYC

**TRUST
WORKERS**

FEATURING COMMUNITY HEALTH WORKERS (CHWS) AT THE FRONTLINES OF PUBLIC HEALTH



What are trust workers?

Community Health Workers (CHWs) are the artists, creators, and main protagonists of our collection. They occupy a critical position as *Trust Workers* in our city's public health system. CHWs are the bridges that help connect hospitals, health providers, doctors, city and social welfare agencies with NYC's diverse communities. Their jobs have many sides. CHWs communicate medical knowledge in culturally resonant ways, they provide access to vital social services, and they turn an empathetic ear towards their community's needs.

Our photovoice stories take you on a journey into how CHWs meet the daily challenges of improving their clients' and patients' wellbeing. Their personal accounts shine a bright light on the day-to-day encounters and relationships shaping how CHWs obtain, repair, and build trust. With this exhibit, we celebrate the important work of CHWs at the frontlines of the city's public health system.

**EXPLORE OUR
EXHIBIT THEMES
ONLINE**



**| FEATURE VIDEO
THE TRUSTWORKERS EXHIBIT IN A
NUTSHELL:**



**| TESTIMONIALS
CHWs ON THE ROLE OF TRUST IN
THEIR DAILY WORK:**



1

WHAT TRUST MEANS TO CHWS

Community Health Workers (CHWs) know their community and speak its language. CHWs build trust through their enduring presence, empathetic listening, client advocacy, and support in navigating medical and social welfare systems. CHWs often live in the communities they serve and are culturally representative of them. As such, they are respected sources of education, information, and translation of knowledge. Being a CHW means having intensely personal conversations with clients beyond delivering medical services. It means listening to their mental health, social, and nutritional needs to help fulfill them and improve the community's quality of life. For many CHWs, trust is therefore built on more than the transmission of "good" or "correct" information. It is built through daily human contact and a deep commitment to their communities.



GUILLERMA MARTINEZ

Trust in the community is earned through the day-to-day work of CHWs, their permanence, and the help they give to the community. It's a natural connection. In my experience, doing my work with my heart is like putting myself in their shoes. Even if you are not the solution to all their problems, you can help by connecting them with the right resources. Trust is time, dedication, and persistence. It's empathy, compassion, attentive listening,



JOHANNA QUEZADA

Trust comes in many different forms. The trust walking into a doctor's office vs. allowing someone into your own home creates different dynamic forces. Participants have to trust doctors and other professionals because of their expertise, and they are assumed to know their job. Working as a CHW, trust is earned differently. CHWs earn trust by getting to know the participants personally, connecting and sharing their

2

HOW CHWS BUILD OR REPAIR BROKEN TRUST

The pandemic has revealed that many Americans lack trust in medical and scientific authorities. Especially for communities of color, a long history of discrimination, exploitation, and neglect has fueled mistrust in the public health system. By nature, trust is not freely given. It must be earned and maintained, and it can be destroyed faster than gained. Fear and skepticism of doctors, hospitals, or vaccines are palpable in the daily encounters between Community Health Workers (CHWs) and their clients. In many interactions with their community, CHWs take on the difficult task of repairing the trust that has been lost, squandered, or that never existed. CHWs know that trust is not always given automatically; it often must be earned through continuing community engagement. Trust is like a brittle plant that requires gentle care, one drop of water at a time.

ANNY ROSARIO

For many reasons, this light blue stand from the Government offering free phone services could be seen as a sign of mistrust in my community. Many families I worked with in the past have spoken against it, believing that their personal information, such as IDs, home address, Medicaid information, etc., would be taken and used for fraudulent activities by unknown individuals. Even though many families know that this resource can help lower some financial stressors at home, some decided not to apply for free phone assistance. As a CHW, it is my duty not just to connect families with services and resources in our community but also to teach my community about them. Most importantly, I help community members understand why these resources are being created in the first place and how they can benefit from using them. After responding to questions from community members regarding the benefits of applying for a free phone, many end up feeling more comfortable giving their private information to me or other CHWs who can assist with free phone applications and other government services.



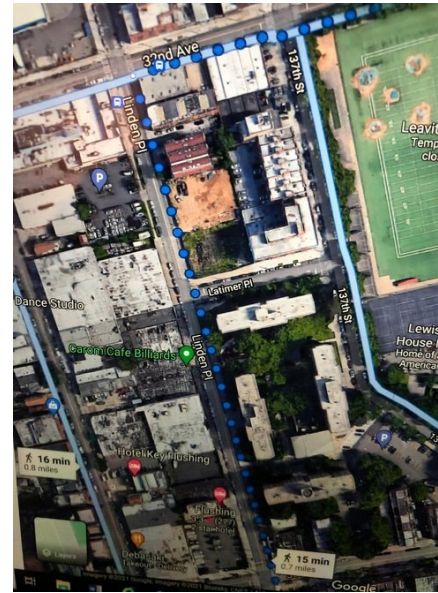
Jaunia Coombs-Clarke

This group showed me how important it is to have trust and “buy-in” with the community. The first time I did a presentation, they barely interacted with me, and it seemed like they were uninterested in what I had to say. The next time I went to do a presentation, they were much more open with me because they were comfortable. I was no longer a stranger disrupting their routine but someone they could trust and accept information from. They answered questions and shared their own health tips and personal things from their lives. Trust within the community isn’t something that is automatically given. It may take several interactions with an individual or a group before they can openly accept that you are there to help or share information.

3

HOW CHWS USE TRUST TO EFFECT CHANGE

Trust is a powerful tool to effect change. As trusted community members, Community Health Workers (CHWs) address a wide range of social and economic issues, including access to education, technology, transportation, food stamps, and medical services. These conditions are commonly referred to as social determinants of health. Adopting this wide social lens allows us to discern that community health is not only the domain of hospitals, health clinics, and doctors. Health is also addressed in many places where people live, work, and worship. CHWs navigate all of these spaces daily. They run programs that bring health education to patients, raise awareness about healthy nutrition, heighten understanding of risk prevention for common health diseases, and offer assistance with everyday tasks. CHWs alleviate the small and large burdens in the lives of their community.



Ingrid Barreda

In one instance, an illiterate participant needed to go to her doctor's appointment but was unfamiliar with how to get there. She confided in me that she was unable to read or write in English or her native language Spanish. She did not know how to get to her medical appointment because she was not familiar with the place, and it was her first time visiting this particular clinic. She also told me that she didn't know how to use a smartphone, so Google Maps was unfortunately not an option. Because of the pandemic, I couldn't accompany her to her doctor's appointment. The participant and I agreed to get on the phone during her commute so that I could try and guide her to the clinic. I had the idea of sending her a screenshot of the directions she needed to follow from Google Maps. Using the picture, she was able to follow the directions to get to the clinic. I then guided her back home safely by using Google Maps while on the phone with her. The participant had trust in me and my guidance and was able to arrive at her destination and receive the medical care she needed. The participant and I utilized this same method several times thereafter whenever necessary.



Marielena Chacón

These steps represent access to the outside world. For a family with a relative who requires a wheelchair, the story can be very different. I visited this family several times while working with them. **I took the picture because I wanted the medical team at my clinic to see what it was like for this family to leave the house every time, they went for a medical appointment with their family member. Most importantly, I wanted to help this family get multiple doctor's appointments on the same day.** Many families can't find an affordable and safe apartment with accessibility. Families end up in relatively safe and somewhat affordable places like this one, but they go through extreme challenges carrying their children and their wheelchairs up and down such steps. Their daily routine becomes an absolute physical challenge. They do this daily to attend school and go to doctor's appointments. As CHWs, we can often assist them by scheduling multiple medical appointments on the same day or by creating online profiles for them on the city housing lottery's website. However, we also often feel frustrated because we can't change some of the housing conditions many families in our communities face.



Community Health Workers' Critical Role in Trust Building Between the Medical System and Communities of Color
Cristian Capotescu, Tashi Chodon, James Chu, Elizabeth Cohn, Gil Eyal, Rishi Goyal, Olusimbo Ige, Jack LaViolette, Sarah Mallik, Lula Mae Phillips, Paulette Spencer, Danielle Lee Tomson *The American journal of managed care* Volume 28 Issue 10 Pages 497-499

Public Philosophy Journal under the title The TrustWorkers Project: Challenges and Methods of Building Trust into Public Scholarship. Public Philosophy Journal (2023) Capotescu, Gomez, Eyal, LaViolette, Tomson, et. Al. In-press.

This is the statue of J. Marion Sims which stood at this site in East Harlem from 1934 to 2018.

J. Marion Sims...“Father of Modern Gynecology” or an example of the systemic racism that exists within the medical community?

Former statue of Dr. James Marion Sims - the "Father of Modern Gynecology"



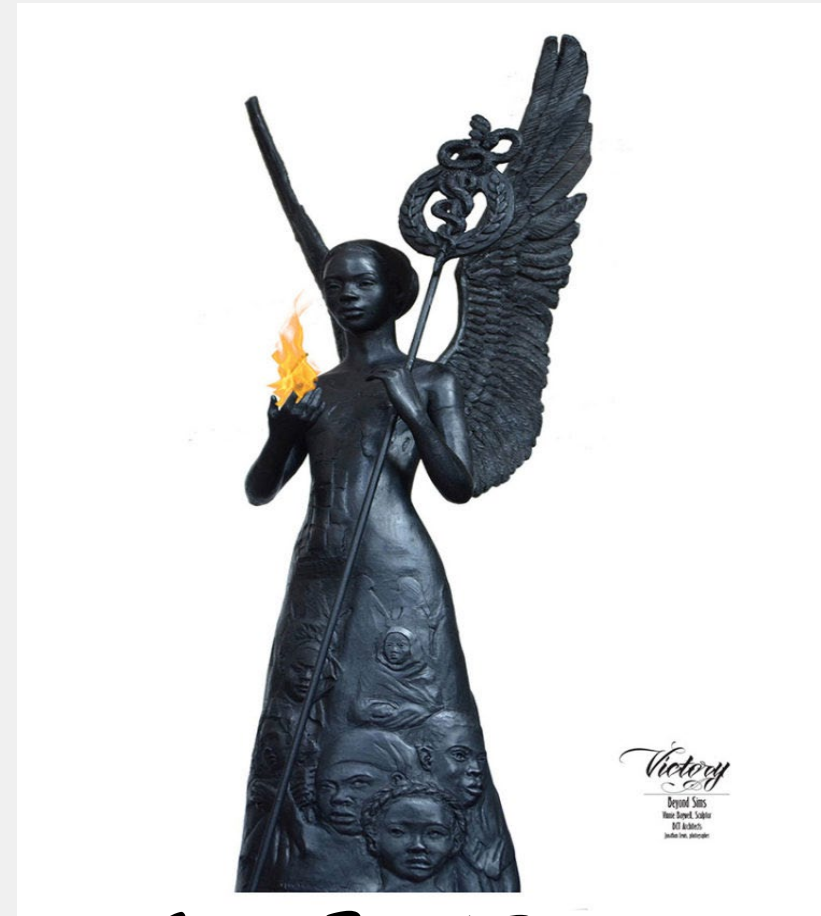
How? A series of forums (2019, 2021)

What? Presentations from artists

Vinnie Bagwell (and her art piece) was chosen with input from the community.



2021 – A community forum to meet the artist & view the selected art piece, hear from the community, and begin healing.



Victory Beyond Sims

I. Environmental Justice

Environmental Impact & Environmental Justice Issues

East Harlem/El Barrio—Manhattan District 11

DSNY Sanitation Garage at E 99th St (1st Avenue)
Sanitation Trucks Parked Along 99th St.

Dilapidated Structure

Adjacent to Metropolitan Hospital, Senior Housing, DOE School



DSNY Consolidated (Districts 1,2 & 5) Garage at Spring Street

Mechanics Bays

Personnel Areas

Garage Offices

Vehicle Access Ramp

Green Roof

VS.



Community members and researchers can get involved & stay involved

Work together towards solutions:

- Identify an appropriate site for its relocation with **equity** in mind [Proposed relocation: Potamkin-M-11 Garage Site _ photo]
- Strive to construct a structure that is **environmentally sound & environmentally friendly** –state-of-the-art – modern – LEED gold certified.
- Support and advocate for a **healthier** EH community – long suffering from chronic health conditions, i.e., high asthma rates, air pollution (high levels of the most harmful air pollutants and fine particulate matter), highest rates of avoidable hospitalizations among adults and children, and among the highest rates of obesity, diabetes and hypertension. *

Continue to inform & engage:

East Harlem/El Barrio --- Community at large

Manhattan Community Board 11 (*former member*)

Community Advisory Board at H+H/Metropolitan Hospital (*former Chair*)

Elected Officials: Councilperson Diana Ayala, Assemblymember Robert Rodriguez, Senator Jose M. Serrano

WeAct (*current member*) and other such relevant groups/organizations

NAACP's Mid-Manhattan Branch (*current Secretary*) & Hazel Dukes, NAACP and Health Committee Chair-Community Board

10

DSNY District 11 Community Advisory Group

*NYC Department of Health-Community Health Profile 2018: East Harlem

Potamkin – DSNY M-11 Garage


Work in Progress: Potamkin - DSNY M-11

Anticipated Completion: MARCH 2022
Owner: Potamkin Development Co. II, LLC
C/O Potamkin Automotive Group
5800 171st Street
Miami Florida, 33015
703-509-1800

For Additional information:
www.ewhowell.com
General Contractor:
E.W. Howell
37 W. 37th St.
New York, NY 10018
212-930-1050

To anonymously report unsafe conditions at this worksite, call 311.
Para reportar condiciones peligrosas en un sitio de trabajo, llame al 311.
No tiene que dar su nombre.

To see other permits issued on this property, visit www.nyc.gov/buildings



The rendering shows a modern, multi-story building with a prominent central tower featuring a circular logo. The building has large glass windows and a mix of light-colored panels. It is situated on a street with a few cars and a green lawn in the foreground.

MARCH 2022
Potamkin Development Co. II, LLC
Potamkin Automotive Group

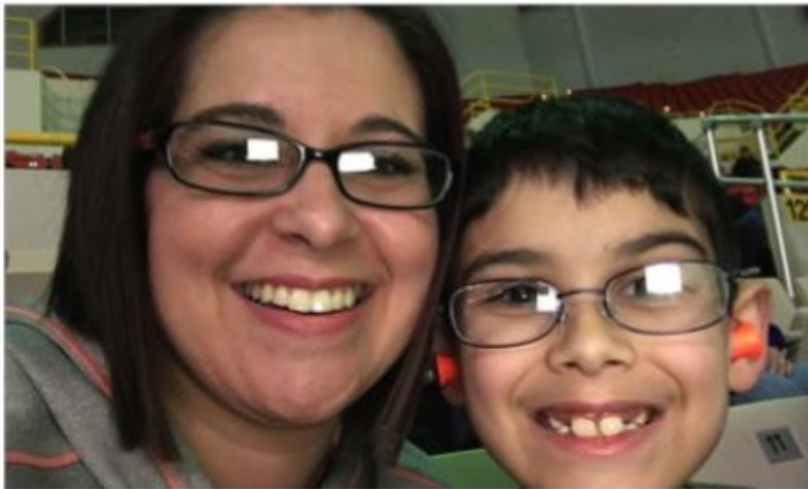


itions
en un

Understanding Autism

Please take two photographs that respond to the prompt:

- **What in your daily life represents genetic testing for autism and return of results'?**
- **What does genetics mean in the life of an autistic person'?**



Maryann

On Diagnosis and Daily Life

It wasn't just that we both wore glasses. When my son was diagnosed with Asperger's at age 9 and it explained a lot in terms of my own life and life experiences, and I understood more than I could ever explain about his. I have come to understand that when our children are diagnosed, it also gives us a chance to examine our own ways of being, how we are in the world. It's becoming clearer, it's in focus now. We have pieces and parts handed down to our children. This he got from me, and I, from my father.

One thing that is so very different is diagnosis. We didn't have the forms of diagnosis, of awareness that we have now. We just had some kids who were different, a little off, an odd man out, their own drummer. My father is a successful scientist and writer. But looking back it is all so clear. So, I guess the genetics cleared up a lot for me in terms of the why.

I'm still struggling with what it means as he is growing up and as I have grown. As I resolve Carter's issues, I realize I have not resolved my own. So, the solutions are sometimes one for him and one for me. Weight issues, noise issues, exposure issues, disclosure issues. Frustrations with others and myself. I am watching them all unfold each day, and hopefully, with each day unraveling them just a little more, and healing both of us.

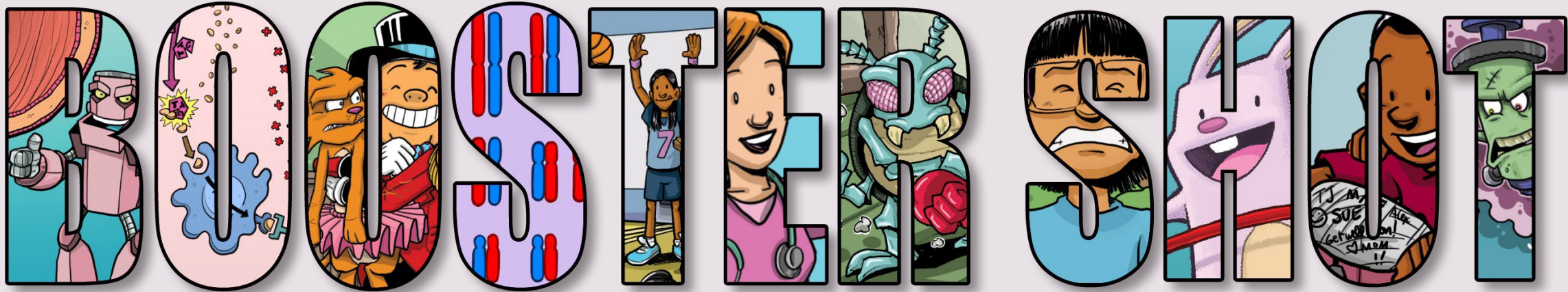


Devin

In my everyday life, the way genetics affects me most is the sensation of touch. The touch thing is as close to universal as they come. Sometimes autistic people crave touch; sometimes they cringe from it. For many people, these sensations are so intense that they take measures to shape their 'touchscape.' I know some who pile on heavy blankets at night for the extra weight; others cut off their clothing tags. In my family, a common expression is "my socks feel weird", which started as just being about socks, but became an expression for all types of skin discomfort with clothing or skin pressure. Some say this is the beginning of understanding some of the biology of autism and how we are made differently, genetically and otherwise.

What is the best use of visual or artistic approaches?

- Other practical uses?
- Aspects we could have improved or done better or differently?
- Thoughts on the integration of science and arts to improve understanding/impact?



Visual Storytelling
Gary Ashwal, Booster Shot Media

ELSI Friday Forum
April 14, 2023





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is a health-focused
creative company.**

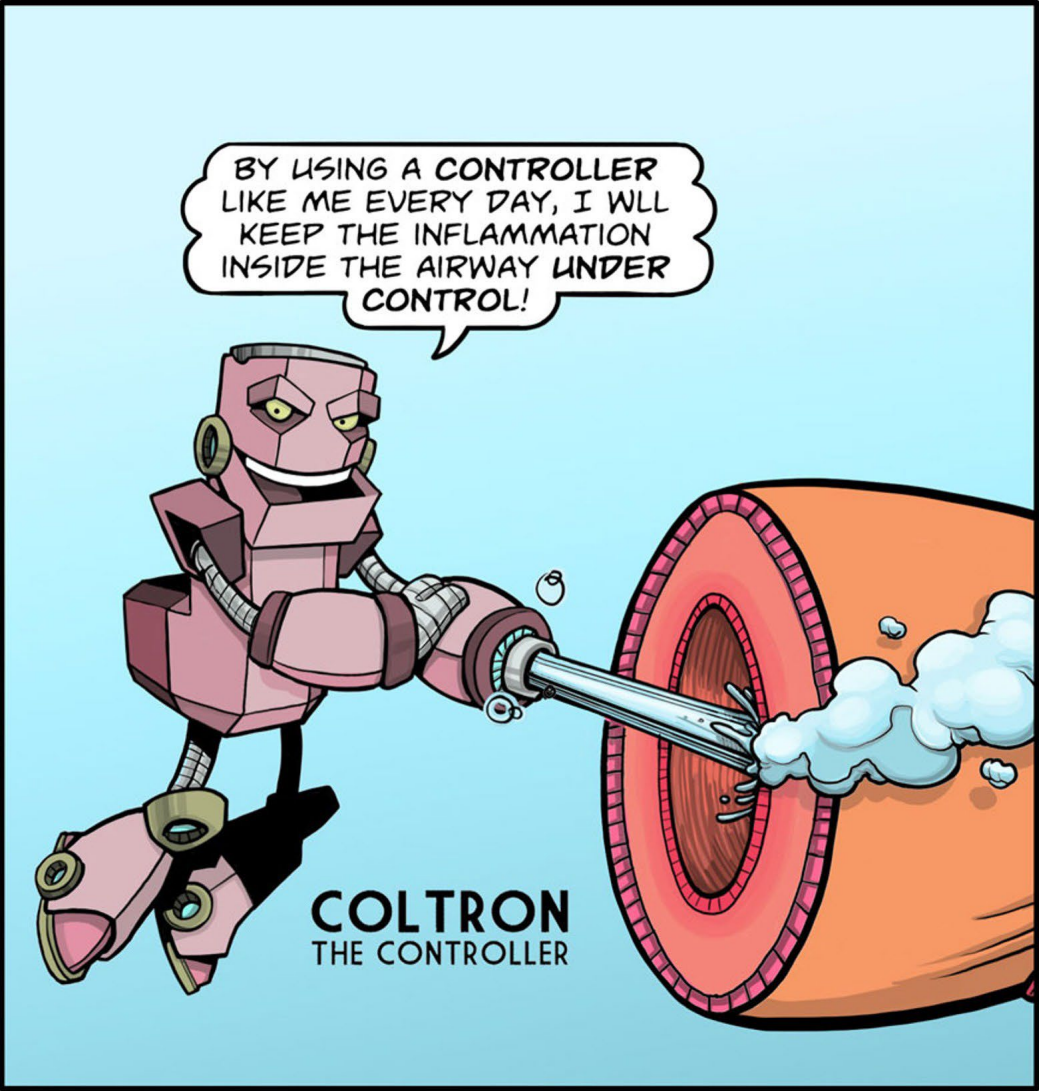
Disclosures

BSM is a for-profit company that produces work for:

- NIH-funded research.
- Children's hospitals.
- Healthcare non-profits.
- Pharmaceutical companies.
- Medical associations.
- Other research, patient education, and public health projects.

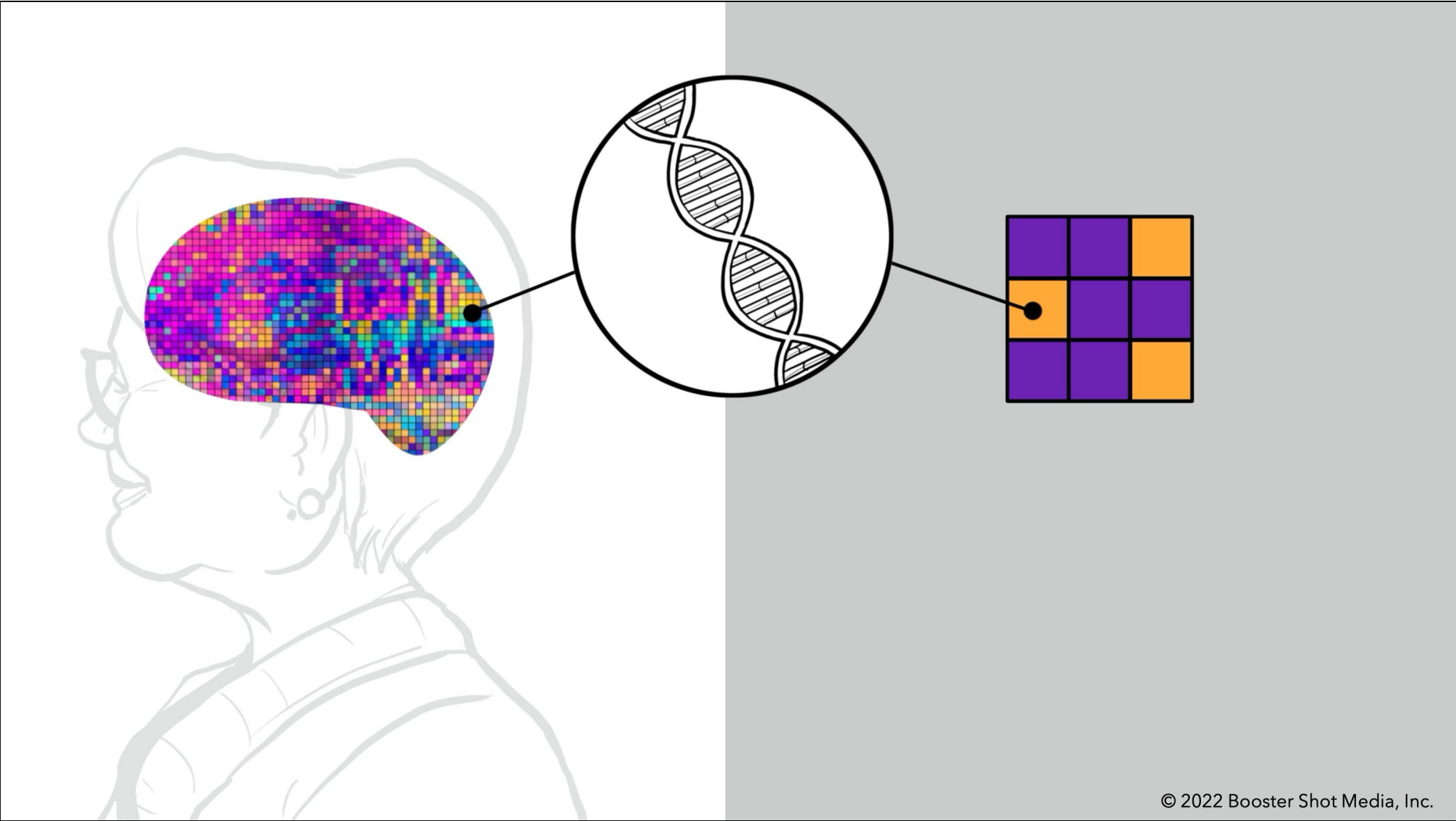


Communicate complex information.



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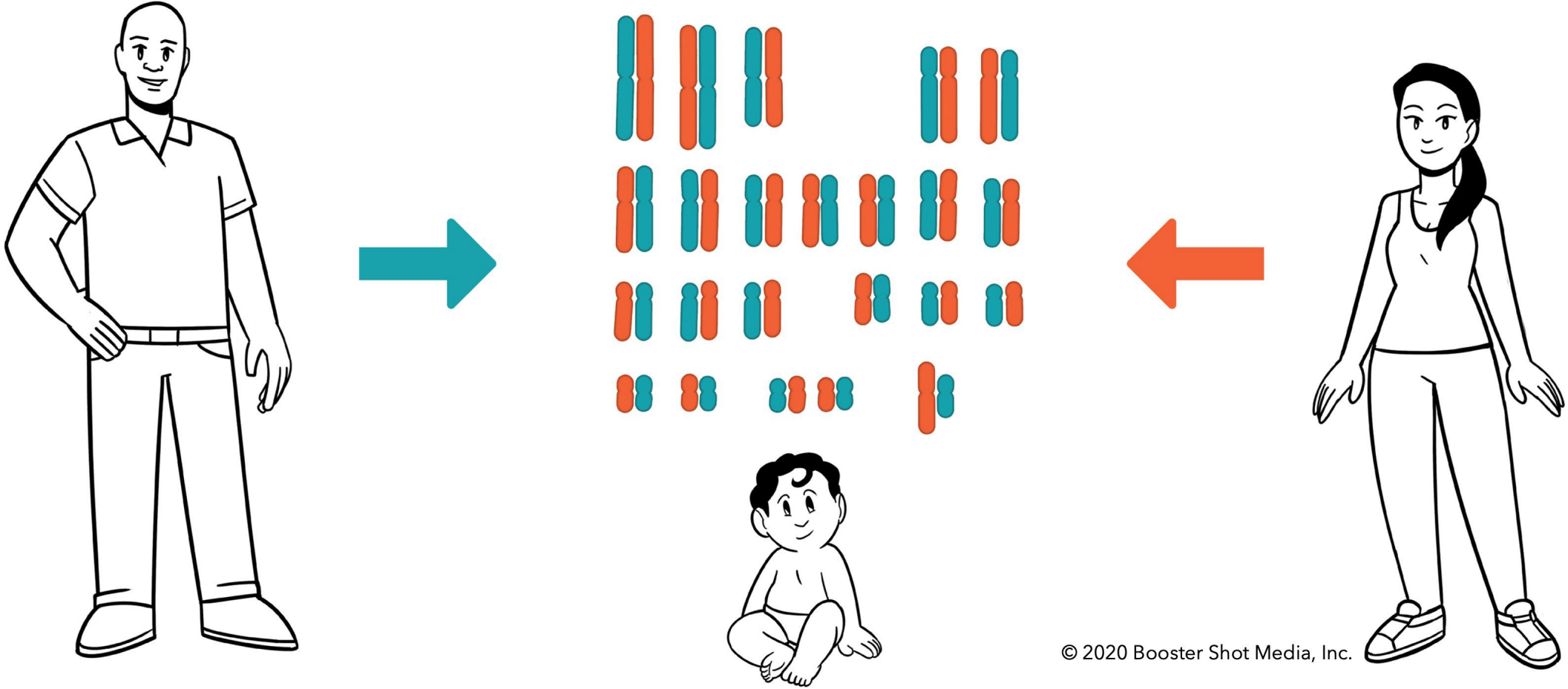
Prompt focus group and survey responses.



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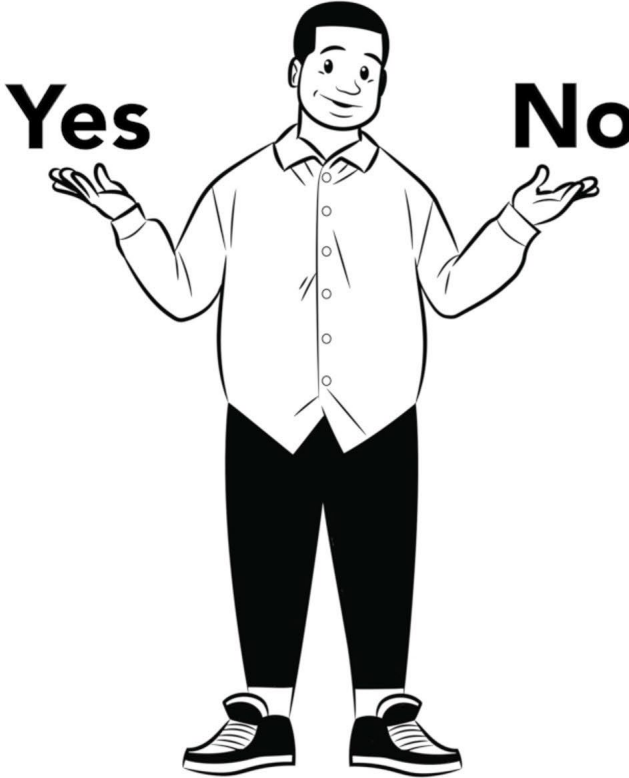
What are brain organoids?

Introduce concepts before a conversation.



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Reinforce ideas during a conversation.



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Provide the structure for a conversation.

Family Reflections Home About Glossary Characters Topics Feedback

Considering The Options **Topic 1A**

"Trach and Vent" option for your child

Parents may look at the ["trach"](#) and ["vent"](#) option differently. You may also hear the term "home vent" for a ventilator that can be used in your home.

You can listen to two different family experiences below.

Marta & Tomas

▶ "When the doctors told us about the trach and vent option..."

[+ Read transcript](#)

John

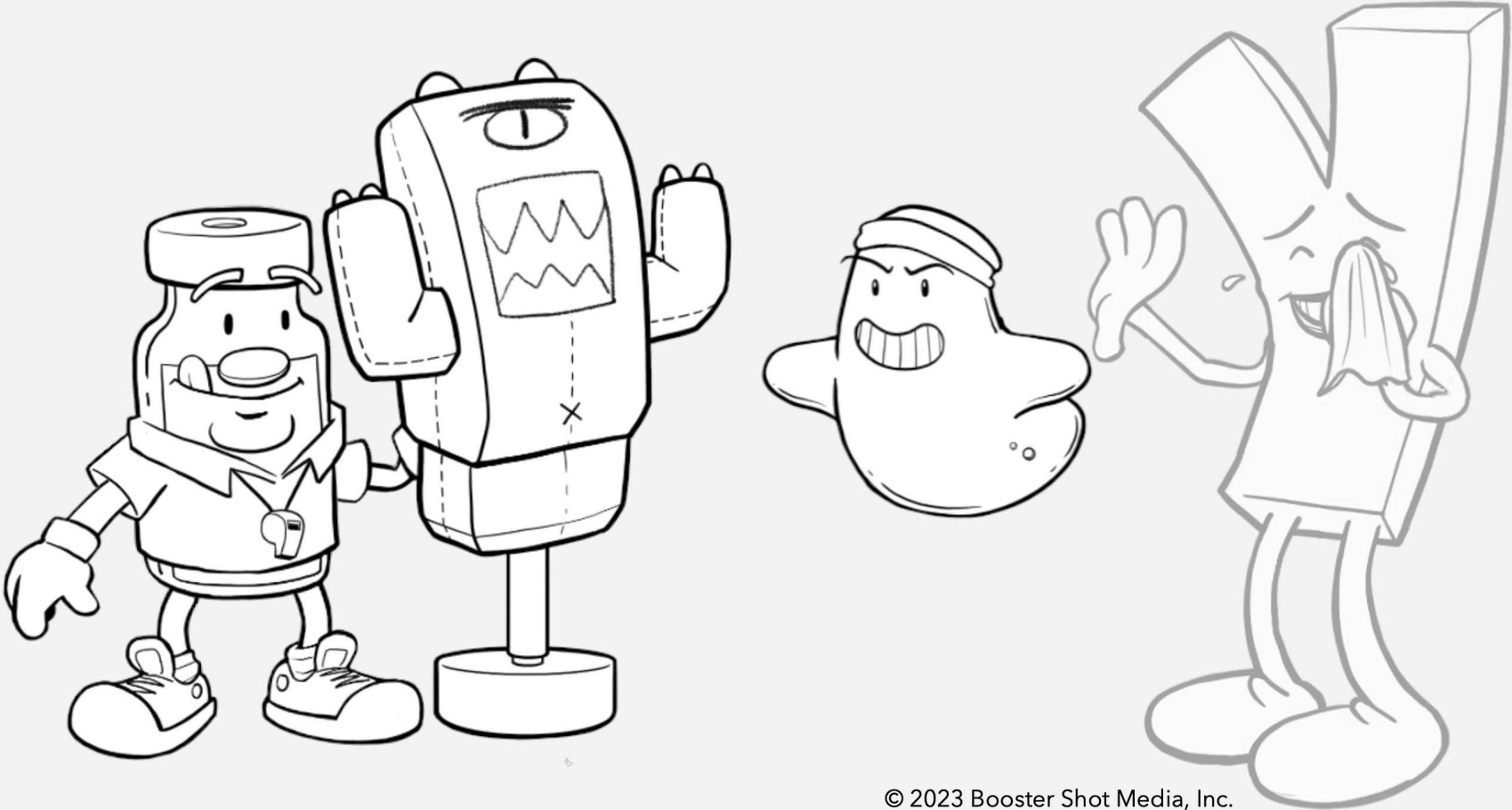
▶ "I know some parents choose the trach and vent option, but..."

[+ Read transcript](#)

[Go to next topic →](#)

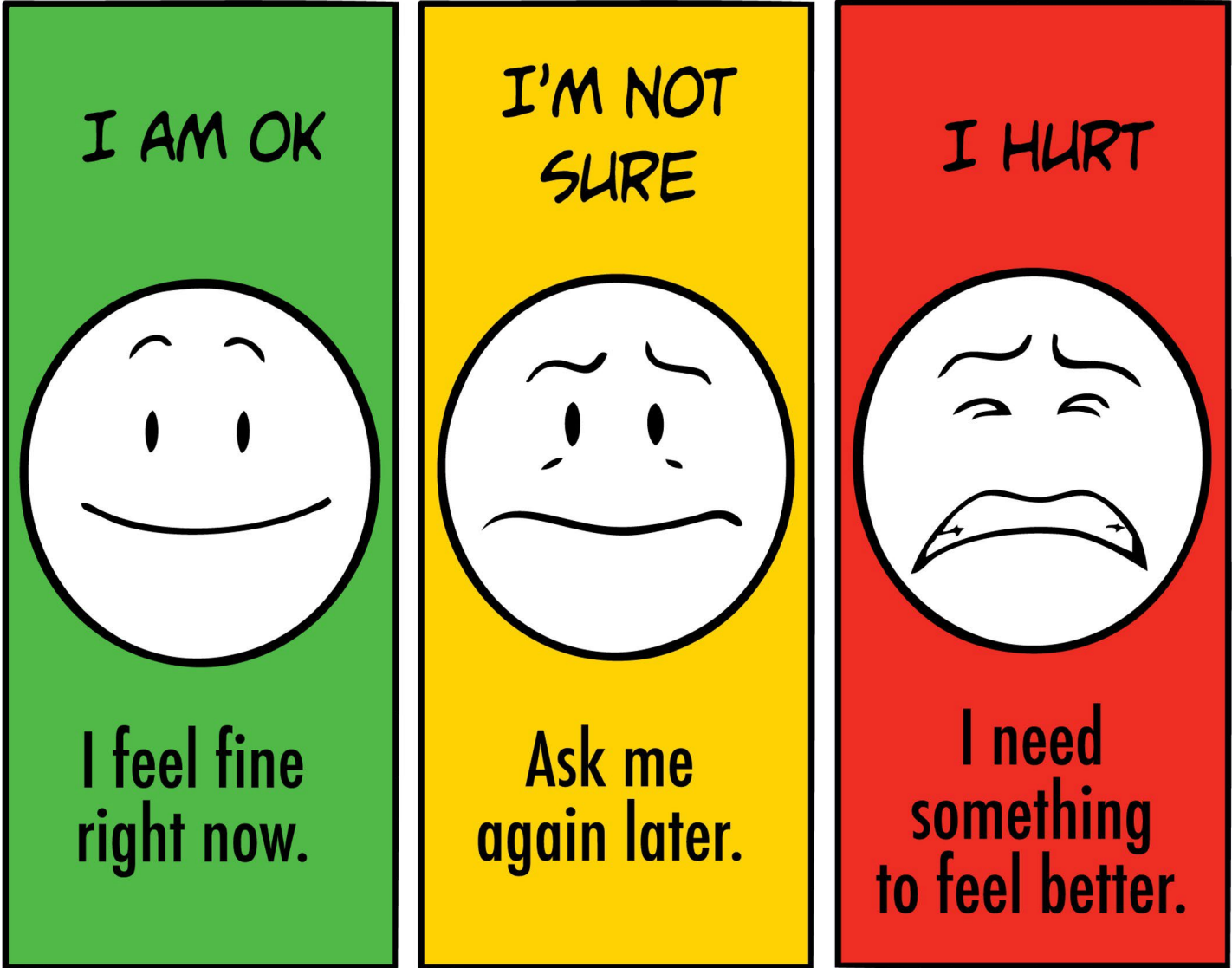
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Reframe concepts to invite open conversation.



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Simplify communication.



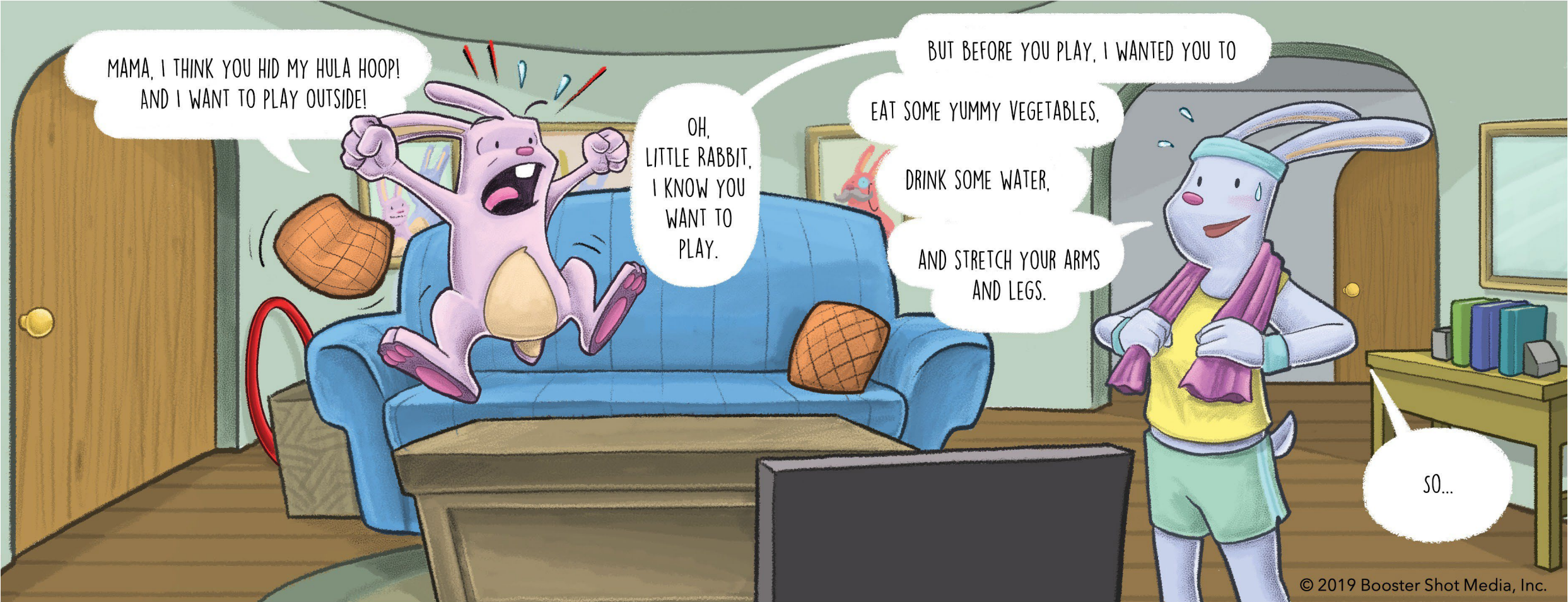
Stoplight Pain Scale™
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and Amy Drendel DO

Encourage conversations in public space.

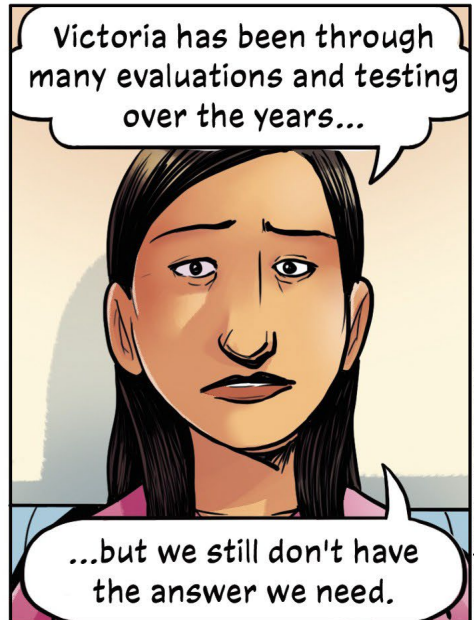
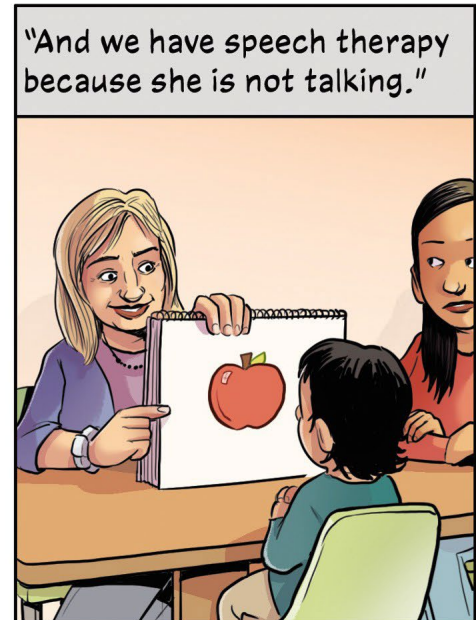
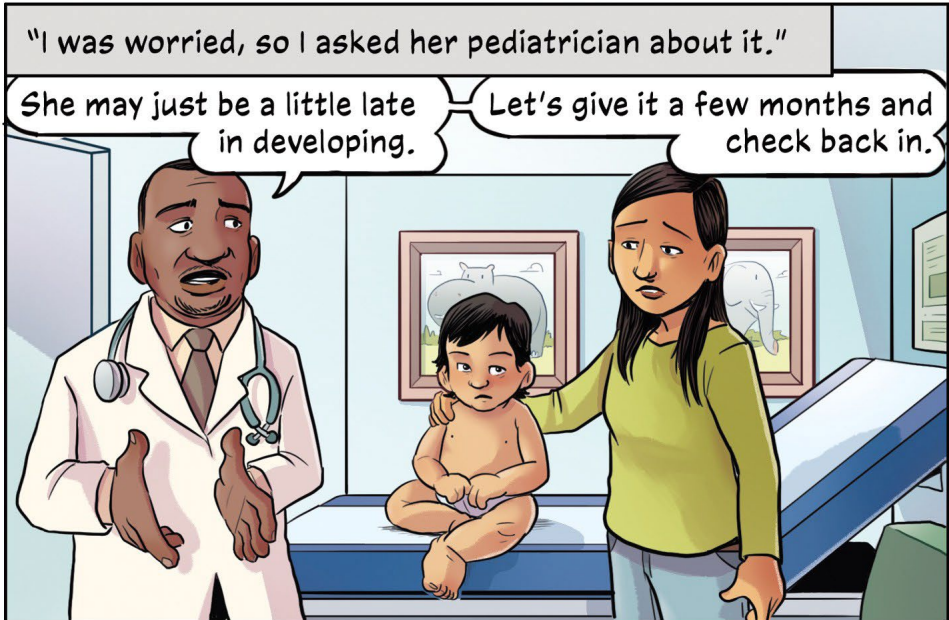


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Encourage conversations at home.



Reflect and extend conversations after research.



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Value and Values in Payment for Gene Therapies

May 12, 2023 at 12pm ET/9am PT



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R. Brett McQueen, PhD
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Moderated by
Hadley S. Smith, PhD, MPSA
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Harvard Pilgrim
Health Care Institute**