



Meeting Coronavirus Personally (sorry this is a little longer than usual)

It started as sniffles. Those were easily chalked up to seasonal allergies. I had been careful to social distance and wash my hands regularly! I wiped down my door knobs and counters and other surfaces with disinfectant.

I woke up early that Friday in May to prepare for a webinar. I was asked to share how patients could prepare for the potential of hospitalization for themselves or loved ones. It was still early in the Mountain West when the webinar was over. Then suddenly I felt like I couldn't breathe. My entire body ached. I was drenched in sweat. At only ten in the morning I crawled back into bed and slept until five pm.

The coughing really kicked in then. I had a frequent, non—productive cough. I cancelled my appointment for a haircut, my first since January. I downloaded the Utah Healthy Together APP, designed to support COVID patients, testing and contact tracing. The APP recommended I get tested. I called to be screened and went to drive-in testing at a local clinic. The nasal swab did not hurt.

The COVID-19 test was negative. But I felt awful and continued to have an unproductive cough. The APP said to quarantine as if the test had been positive. After all, twenty percent of all negative tests were actually positive. My whole body hurt, especially my chest, and my head not only hurt. I was having trouble thinking straight.

Toward the end of the week, my electronic medical record alerted my Doctor that I had been tested and she started to try to touch base with me. Almost two weeks after my first symptoms, my Doctor and I video chatted using the Intermountain Connect Care App. She called or messaged me on the EHR portal every day or so for the next several weeks. Over the Memorial Day weekend my breathing issues worsened. Friends urged me to be seen in person. On Memorial Day I dragged myself to a walk-in urgent care clinic. I was having increased trouble thinking. I had developed a metallic taste in my mouth I couldn't get rid of. The clinic sent me to the Emergency Room.

The folks in the COVID unit looked a little like robots in their respiratory support hoods and gowns and gloves. They were all very kind. I noticed some lapses in infection control and things like not putting up rails on the bed when I was clearly a falls risk. But I was too sick to really advocate effectively for myself in the moment. And I was alone. They tested me for COVID. This time the swab hurt. It came back negative.

After an aerosolized treatment my breathing improved and I drove toward home clutching a prescription for steroids. I dropped it off at my local pharmacy a few blocks from home. The Pharmacy was supposed to provide delivery. Two days later, my neighbor went and picked up the prescription for me because the Pharmacy forgot to send it. Slowly I improved. Very slowly.

My Doctor continued to call regularly. She said that in all likelihood, I was indeed battling the Coronavirus. She said no other viruses were currently circulating and all my symptoms were in line with what they were seeing. In CDC terms, I would be considered a "probable" case. But my case is most likely NOT counted in Utah's numbers. I never tested positive for COVID-19.

For a few more weeks I felt like I could barely move. I perked up enough for a call here or there, or to answer my email, and then retreated to bed for hours on end. My dog seemed to understand something was wrong and did not even ask to go for a walk. My neighbors brought me meals and checked on me regularly. I may have watched every episode of Maine Cabin Masters.

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I found while I could push through a day working, it would mean the next day or two down again. I started experimenting with pacing myself to be up for an hour or so and then rest for an hour or so. That seemed manageable and I began to get more work and household chores accomplished.

I started walking the dog. First, we just went a few blocks. We've now worked up to about a mile and a half a day. After eight weeks, I am getting to the point where I feel almost back to normal.

In a week or so I will have antibody testing. And a physical. The virus can wreak havoc on the heart, kidneys, liver and more. I mentioned to my Doctor that maybe now I could go visit my son in Manhattan. She said, not so fast. We don't know if you will have immunity to this virus going forward.

I appreciate that Rachel Weissburg and her brother, Josh, shared their story with us in previous newsletters and on our YouTube series, **Three Voices: One Conversation – Patients, Families and Providers discuss Covid-19**. Knowing that Josh also battled an unconfirmed case of COVID-19 for a few months helped me understand that, unlike the flu, this may not clear up in a few weeks. Watch Josh's story here: <https://youtu.be/4-bSUO4NH-o>

In this Newsletter, read on for:

- Our interview with **Lisa Freeman**, an extraordinary Patient Advocate from Connecticut.
- So many persons liked our Graphics, we have included another **Graphics Garden** for you!
- Links to the YouTube Series "COVID-19: Patients, Families and Providers in Conversation."

The **Three Voices: One Conversation** series offers several insights into issues around handling COVID-19. I was especially struck by Dr. Swati Gaur, MD, MBA, CMD, AGSF (Chair, Infection Advisory Committee, Society of Post-Acute Long Term Care, Georgia) sharing the response her team has had in caring for patients at the New Horizons Long Term Care Facilities. Dr. Gaur noted that they urge the team to bring any issues with infection control to a team member's attention. This is called "supporting the team," rather than a lapse or problem. Instead of catching a colleague doing something wrong, they promote doing something right. This simple reframe can serve to make the entire culture more conscientious and caring.

Check out the entire series, produced in partnership with Project Patient Care and the Healthcare and Patient Partnership Institute, on the CAPS YouTube Channel:
<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

If you or someone you know contracts the COVID-19 virus, they may or may not have a multi-week course of illness and recovery. The virus seems to have a range from no symptoms to severe disease requiring hospitalization. Unlike the flu, however, a patient should not be expected to recover and return to work or full activity in a week or two. We have made many adjustments to work and social activities to accommodate the COVID-19 Pandemic impact. One policy change may need to be longer leave allowances for illness.

I am very thankful for the support of my friends, neighbors and colleagues. I remain concerned about misinformation. Some friends of mine were certain I would die or that I would necessarily end up on a ventilator in the hospital. Still other friends still don't understand how to protect themselves with masks, hand washing and appropriate physical distancing. For these people, I do not think shaming will be an effective way to support their infection control efforts! Rather, we need to reinforce that we care about persons wanting to stay healthy. Snarky memes will not help persons stay healthy. Providing masks, providing hand sanitizer and offering social distance tips may.

Please let us know what topics you would like us to address in the **Three Voices: One Conversation** series. And, please do what you can to stay safe and not be a probable or confirmed case of COVID-19. **-Lisa Morrise**



Consumer Advocate Panel (CAPS CAP)

Interview with Lisa Freeman

Lisa Freeman, Executive Director, Connecticut Center for Patient Safety, has been a patient safety advocate for over 20 years. Lisa also represents the patient perspective and works on patient safety at the state and national levels including the Connecticut Department of Public Health-Healthcare Acquired Infections multidisciplinary committee, Connecticut's All-Payer Claims Database Data Release Committee, the Connecticut Board of Nursing, the National Quality Forum, the Patient Centered Outcome Research Initiative, and the Consumers Advancing Patient Safety Consumer Advisory Panel.

CAPS: When did you start your advocacy?

Lisa: When my husband Rory, was injured I had to be a strong voice. While I'd always advocated for my kids' needs, this was different. Rory went into the hospital due to a back injury and Doctors decided he needed emergency surgery. That surgery did not go as expected and Rory was in the Operating Room for 18 hours. The end result was he was paralyzed from his waist down and suffered brain damage, along with a MRSA infection in the wound.

He was in the Intensive Care Unit for five days and the hospital for two months. He was transferred from there to the Acute Rehab facility for two more months. His mental acuity was not the same. I suddenly had to learn how to meet his specialized care needs. I didn't see any option but to become his advocate and then, advocate for others so they wouldn't be in the same position.

CAPS: How has your advocacy evolved?

Lisa: My role as an advocate was an education by fire. It was a day to day growth that evolved without me realizing the increasing role I was taking on. Information has to resonate with me. In Healthcare, there is a different culture and language than what I, or most people, was used to. I had to dive into that to be effective for Rory. It was kind of like going to college. I always stayed with him when he was in and out of the hospital. I became a "helicopter Mom" to my husband!

I focused on learning everything I could. I was never satisfied until I understood what was being done or what was happening. I learned to provide more and more of Rory's care, so he did not have to be hospitalized as often. Because of the care I was able to give, I gained the respect of the specialists that cared for Rory. They started to ask me to represent patient perspectives in different settings.

Rory passed away after almost eighteen years of enduring lack of mobility and pain. I then became even more involved in advocacy roles and worked closely with the Connecticut Center for Patient Safety.

CAPS: What projects have you been involved in?

Lisa: I have mostly focused on educational outreach. I am trying to create a base level of comfort that community members have in their understanding of Healthcare. I call it Patient Safety 101. We teach patients about medical error, medication management, infection prevention, the difference between hospitals, and the hospital rating systems. And we empower patients so that they will be more engaged and activated in their or their family members' health care. By

empowering patients, it has been shown that they can achieve better outcomes. We teach them how to ask questions and, we provide resources for additional support.

I've also been involved with Quality Measures with the National Quality Forum. Most patients are not aware of measures and how the questions they are asked about their outcomes impact reimbursement and care. Over the last few years I have been addressing issues involving diversity and equity as well as racism in healthcare. There are great disparities between people from different cultures, people with different economic status' and education levels. There is no reason that this should be and the gaps and the inequities must be eliminated. One action that we are working on is to get representatives from the large health systems in Connecticut to come to the table and have a series of frank and candid conversations to address the various disparities in our health care systems, the systemic racism that exists, and the way health care is being provided to our residents.

CAPS: What do you recommend to a person who wants to advocate for Quality and Safety?

Lisa: Stretch your reach! Don't be intimidated by what you don't know. If it sounds interesting to you, dive in! You don't have to be an expert in medicine or the business of hospitals. You need to be an expert in being a patient, an expert in being you. Communication should go two ways. As an advocate you have just as much right to understand as others may have to be heard, so don't hesitate to ask questions.

CAPS: What do you recommend to Healthcare Systems that want to improve Quality and Safety?

Lisa: Work on becoming truly interactive systems. Having individuals functioning in their own silos alone no longer works. Even if just you are responsible for just one aspect of a patient's care, remember that the whole patient is involved! Remember that the person is always a person and only visiting you when they are a patient. Medical communication needs to systemically include patients in every aspect of the system's functioning from interior design to workflow and policies. The system will be stronger if it considers the patients perspective and safety in all they do, while the professionals in the system maintain their medical expertise and function as a person-centered culture and system.

CAPS: What are your future plans?

Lisa: I want to keep growing personally in my advocacy. That means I will keep doing what I am doing, while continuing to learn and being a part of solutions. I prefer to be involved in groups that take patient safety to the next step and work to solve issues. So long as patients are being harmed in healthcare then there is much work to do.

Read Rory Freeman's story here: <http://www.ctcps.org/r-freeman.cfm>. Contact Lisa Freeman at Lisa.Freeman@CTCPS.org. **Lisa Freeman** is the Executive Director of the **Connecticut Center for Patient Safety**. Here is some of their work:



5 Things to Know

1. [What you need to know in the Hospital](#)
2. [15 Steps You Can Take To Reduce Your Risk of a Hospital Infection](#)
3. [Selecting Doctors & Hospitals](#)
4. [What to do to avoid medication error](#)
5. [AHRQ Director Helps Consumers Navigate the Health Care System in a New Advice Column on the Web](#)

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These are the videos in a series of COVID-19: Patients, Families and Providers in Conversation. These videos are a collaboration of three organizations:

Consumer Advancing Patient Safety (CAPS), Project Patient Care (PPC) and Healthcare and Patient Partnership Institute (H2Pi).

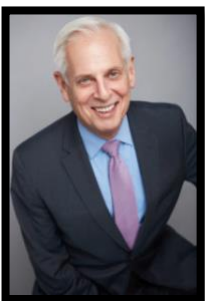
You can view all of these videos on the Consumers Advancing Patient Safety YouTube Channel. Please go the link below and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!

<https://www.youtube.com/channel/UC7f7J8ynAwpDQpJWQX9mjQQ>

- **Preparing for a Hospital Visit** – a conversation with Rosie Bartels
- **Learning from COVID-19 Patients** – a conversation with Josh Weissburg
- **Elective Procedures in Hospitals** – a conversation with Kellie Goodson
- **The Important Role of Telehealth in Mental Health** – a conversation with Wendy Hayum-Gross
- **Health Equity During Covid-19** – a conversation with Ron Wyatt, MD, MHA, IHI Fellow
- **Finding Hope and Meaning through stories** – an introduction to stories with Tracy Granzkyk and MedStar
- **How has the COVID-19 Pandemic affected you personally** – the first of several conversation videos with Helen Haskell, Crystal Morales, Josh Weissburg, Vonda Vaden-Bates, Tim McDonald, MD, Pat Merryweather-Arges, Steve Burrows, Margo Burrows, and David Mayer, MD
- **What stories have you heard or experienced that are COVID related that we can't forget?**
- **What technology or innovations look transformative for the future as a result of COVID-19?**
- **What will this teach us for the future of healthcare?**
- **COVID-19 Testing** – a conversation with Moira P. Larson, MD, MBA
- **Long Term Care Facilities Part One** – a conversation with Pat Merryweather-Arges
- **Long Term Care Facilities Part Two** – a conversation with Dr. Swati Gaur

Consumers Advancing Patient Safety often partners with other organizations seeking to improve Quality and Safety. When possible, we support their efforts here:

Walking/Running/Riding for Patient Safety by Marty Hatlie – an update



I shared here last month about a Patient Safety “March on Washington” on September 17th, Global Patient Safety Day, to raise awareness about a healthcare system that just is not reliably safe. It's a huge, complex problem that touches millions of families across the globe every year. But because it happens one person at a time -- unlike a plane crash, uncontained forest fire or mass shooting -- people just don't realize how massive the problem is. Some hospitals, clinics and nursing homes have prioritized patient safety, but every one of us deserves a healthcare system that work in an organized, principled way to keep us and the people we love safe. That's the point that led the Patient Safety Movement Foundation, where I volunteer, to organize a March.

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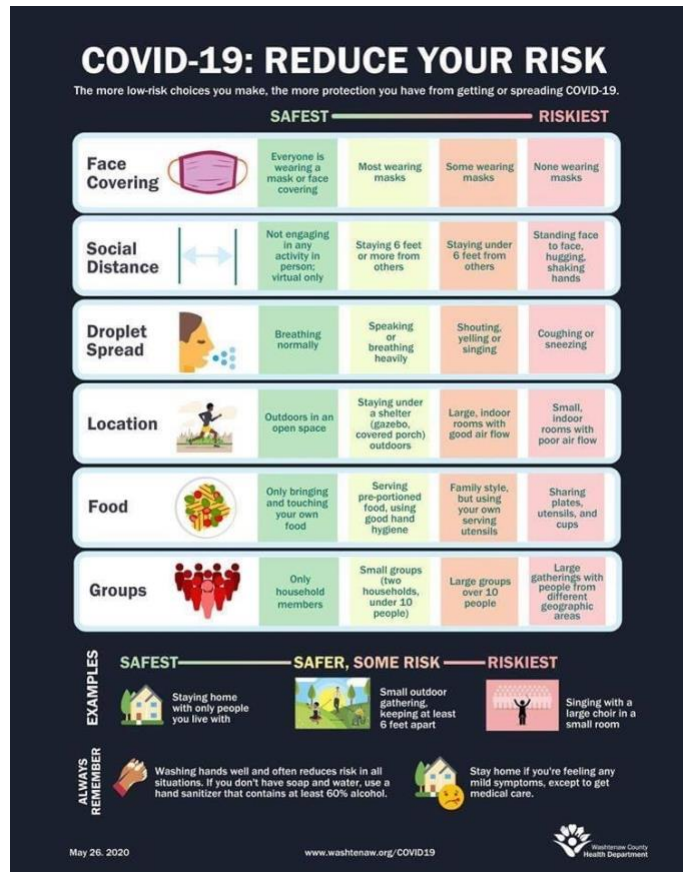
The Covid crisis has now shone a bright light on the gaps in safe healthcare, not just for patients and their families but also for the healthcare workforce. **BUT**, Covid also makes it unsafe for thousands of people to gather and march, and we don't think that will be over by 9/17.

So we've reinvented the campaign as www.UniteforSafeCare.org. It will include a virtual conference and entertainment in the week leading up to 9/17, and a smaller, more symbolic event in Washington itself on 9/17. We're thinking one or two representatives from every state, walking up Pennsylvania from the White House to Capitol Hill with a demand to make safe healthcare an urgent priority.

A group of us are also committed to walking, running or riding a million miles for safe care before 9/17. We're using an app called Charity Miles to collect our steps/miles from fitness trackers and cellphones and collectively count them. If you'd like to follow our plans, or engage in some way, please visit the Unite for Safe Care website to learn more. You can sign up to follow the campaign or get materials to help organize a coordinated event in your own country, state or town. We'd love to see that happen!

And if you'd like to point your steps or miles toward our One Million Miles goal, go to www.CharityMiles.org or download the app on your phone. I bought a Peloton bike to help to keep me sane as I shelter at home and have already ridden 1000 miles and promised myself to do another 1000 by 9/17. Thanks for your support! -MH

The Graphics Garden:



COVID-19 Risk Index

Risk levels for exposure vary based on four main factors:

- Enclosed space**
- Duration of interaction**
- Crowds** (Density of people + challenges for social distancing)
- Forceful exhalation** (Sneezing, yelling, singing, and coughing)

Low

- Walking outdoors** (With or without pets)
- Running or biking** (Alone or with another person)
- Staying at home** (Alone or with members of your household)
- Outdoor picnic or porch dining** (With non-household people and physical distancing)
- Picking up takeout food, coffee, or groceries from stores** (Potential crowding)

Low / Medium

- Playing "distanced" sports outside** (Ex. Tennis or golf)
- Grocery shopping**
- Retail shopping**

Medium

- Visiting hospital emergency department**
- Medical office visit**
- Dentist appointment**
- Taking a taxi or a ride-sharing service**
- Museum**
- Outdoor restaurant dining**

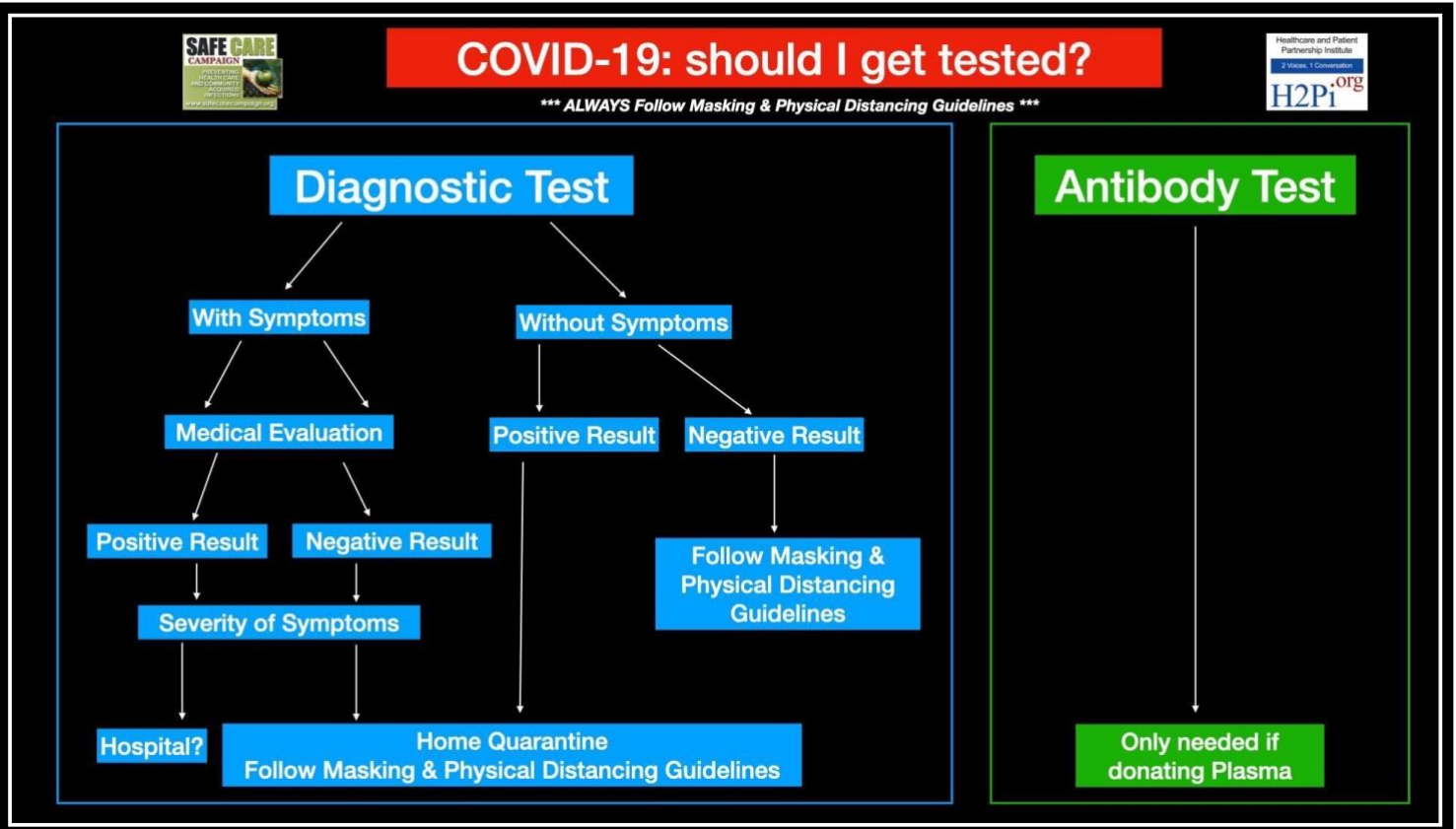
Medium / High

- Exercising at a gym**
- Hair/nail salon and barbershops**
- Working in an office**
- Indoor restaurant or coffee shop**

High

- Indoor party**
- Air travel**
- Concert**
- Movie theater or live theater**
- Bars and nightclubs**
- Playing contact sports**
- Public transportation Subway or bus**
- Religious services**
- Watching sports**

REOPEN INTELLIGENTLY. REOPEN SAFELY.





Stuck home?

Events cancelled?

Worried about getting sick?

Use this time to **TakeCHARGE** and prepare to be a patient with the **TakeCHARGE Campaign 5 Steps to Safer Health Care!**

Step #1 - Understand & Complete Your Advance Directives

Who will speak for you if you can't speak for yourself?

Step #2 - Keep a Record of Your Medical History & Current Medications

Don't expect your clinician to get it right 100% of the time

Step #3 - Prepare for Doctor Visits / Make A List of Questions

Don't forget what you wanted to talk about. Prioritize your questions and remember to share your symptoms

Step #4- Prevent Infections / Ask Caregivers to Wash Their Hands

Infections are a problem. Be respectful, but assertive in asking caregivers to wash. They know they are supposed to wash their hands and may have just forgotten

Step #5 - Use an Advocate / Be an Advocate for Others

An advocate is a helper and can be a family member, a friend or a professionally trained person. An advocate should not take the place of a healthcare professional. Plan ahead for someone to support you and you can do the same for others

www.TakeCHARGE.care – Join the Campaign!

Please visit:

Our web page at www.patientsafety.org. Find resources, archived recordings a form to share your story or sign up for this newsletter!

And, please like our Facebook Page: <https://www.facebook.com/patientsafety.org/?ref=bookmarks>

Do you have information for the CAPS Newsletter?

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Send it to capspatientsafety@gmail.com

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