



I network with many families and persons who live with chronic complex medical conditions. They often comment that they wish their life situation was better tolerated and understood by others. The persons and family members chafe at a lack of accommodations, awkward situations often involving social rejection and comments that range from uninformed to pointedly rude.

My family's experience was no different. There was the time the local play group would not allow my four-year-old to attend because she was not yet potty trained. It would be five more years before we achieved that milestone. There was the group of teenage fellow Church congregants who taunted my child saying they had gone as a class to the local amusement park without her. When I asked the organizing Mom

why they would do such a thing, she replied, "Well, you know how she is." I wryly replied I would have gone with them to mitigate any issues faced by my child's developmental and medical issues.

Then there was the local school Principal who opined she understood why parents wouldn't want their children on the playground with the Special Education children attending her school. They were, you know, so different, she had said.

These kinds of insults are not just perceived but very real and can be intentional. I try to urge those who have been stung by the rude, sometimes callous behavior of others to see that behavior itself as a form of developmental delay. Some people may need extra training in order to achieve the milestone of humanity.

In the medical world persons may also feel the sting of ill-considered comments. There was the Doctor who told me that a mistake I'd made in caring for my child with a tracheotomy and g-tube was, "Not very smart." I told our Pediatrician the rebuke made me not want to see that colleague of his again. Our Pediatrician said, "Oh, you can handle that!" But the remark had hurt and come at a time of vulnerability when my kiddo was very sick. I meant it when I said I chose not to see the insulting Doctor again.

My kiddo, now an adult, deals every day with someone insulting their challenges with navigating the world. These insults are not merely perceived but are very real. Alone they could possibly be shrugged off. Incrementally they cannot be ignored and can interfere with educational attainment, a person's social milieu and their medical care. Would you want to go anywhere you could predict will lead to you being insulted and mistreated?

These sentiments are very similar to what I have experienced with members of my family who are persons of color. The incremental, micro incidents of intentional and non-intentional insults, social exclusion and even medical related bias lead to a rift in the health engagement they should be able to experience with healthcare.

As we grapple with health equity and unlearning years of mistreatment, especially of persons of color, we should look at the incremental incidents that lead to statistical inequity. We need to unlearn thoughts like pain is experienced differently based on skin color, our eGFR should be interpreted differently based on skin color or that any group of people will respond the same way to a treatment based on a group identification. This is why CAPS is building a curriculum to train healthcare professionals how to be part of the Partnership for Healthcare Justice. Stay tuned for more information in coming months about our work to achieve equity. -**Lisa Morrise**

#### In this issue:

- \*An interview with Lt. Colonel Steven Coffee, MedStar PFACQS Co-Chair and member of CAPS Community Advisory Panel.
- \*Sepsis resources from MedStar.
- \*A Challenge from the Patient Safety Movement Foundation.
- \*Information about Pulse Center for Patient Safety Education & Advocacy *Take Charge Campaign*.

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Thank you for your support! -Lisa Morrise

## CAPS Consumer Advisory Panel Profile



**Lieutenant Colonel Steven Coffee** recently returned to the Pentagon from a year-long Middle East deployment in Qatar as the Deputy Director for the Air Force Central Command Program Management Office. Colonel Coffee commanded at the squadron level and served on several staff headquarters staff positions to include the Joint Staff.

Previously Colonel Coffee served as a White House military aide to Presidents George W. Bush and Barak H. Obama on the Social Staff. His and his wife Sezanne's son, named Steven II, underwent a liver transplant at just two months of age. Young Steven is now eight years old. Sezanne is an executive in the finance industry. The Coffees make their home in Virginia, and Colonel Coffee volunteers as a Patient Advocate with the MedStar Institute for Quality and Safety. He also volunteers with the CAPS Consumer Advisory Panel.

### CAPS: When did you start your advocacy?

**Steven Coffee:** My passion for advocacy was birthed from a very painful experience with my son. I would say it started in 2014. At just two months old My son, Steven II—I call him “Deuce”, had a liver transplant in 2012. His transplant not only made him the youngest liver transplant patient in the country, but also the first to have a transplant due to galactosemia—a condition that does not allow his body to break down galactose found in human and animal milk. It also changed my life as a parent by helping me discover my passion for patient advocacy. Steven's galactosemia was misdiagnosed while we were under military medicine. I really didn't realize then, what is so obvious now, the numerous gaps and seams in care. These ultimately led to the misdiagnosis of galactosemia in Steven that resulted in his liver failure.



I recall a time following our transfer to MedStar Georgetown University Hospital where he had the transplant; a member of his medical team discussed ways to increase Steven's weight. He wasn't gaining weight, and they wanted to increase his caloric intake. I wondered why they couldn't just add powdered soy formula to his liquid soy milk. I was told the hospital didn't have powdered formula in stock, just the liquid. And no, I couldn't just go to the store and get some powdered soy formula. I was amazed that their system wasn't set up for what seemed like a simple solution to a critical problem.

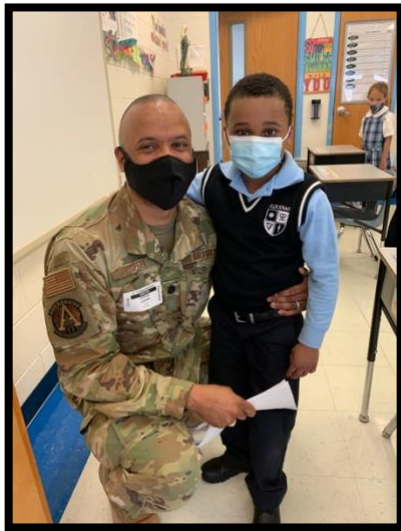
Georgetown Hospital has a motto, “Cura Personalis.” It means care of the whole person. But they really didn't have a mechanism to care for and understand the “whole” patient. In 2014 they set up a PFAC but added a “QS” on the end. It was a PFACQS – a Patient and Family Advisory Council for Quality and Safety. The QS part is significant because it showed a specific focus not only to include patients but also to address quality and safety in patient care.

I was the first community member co-chair, and what excited me then as it does now is how we started to see a way forward to Cura Personalis. As an active duty member of the military, I had experience in managing a High-Reliability

Organization (HRO). I was able to bring my background to bear in the development and management of the PFAC as a lead advisor.

## **CAPS: How has your advocacy evolved over the years?**

**Steven:** Our personal story evolved when Deuce’s mom left one weekend for a girl’s trip. It’s funny because, as any new mom would do, my wife gave me very specific instructions before departing. She said to make sure her baby (as if he wasn’t my baby as well) was fed, not wet and alive. I thought that wouldn’t be too hard. But Steven, due to his immunosuppression medicine, was more susceptible to getting sick. It was the first night, and of course, after what seemed like the 10th time of her checking on us, something changed. It was bath time, and I found it odd that he was shivering in a warm bath. I took his temperature, and it was slightly below the point the transplant team suggested to bring him in if he had a fever. I debated with myself about taking him in but decided to be cautious. As we were driving into the parking terrace, I looked back to tell Steven he would get a stick, and his eyes were rolling back in his head. I spun the car around and drove to the ER entrance, running from my car with doors left open and my boy in my arms saying, “Something is wrong with my baby!”



Steven had gone into Septic Shock. I didn’t even know what Sepsis was. When Georgetown looked at starting a sepsis awareness campaign, I wanted to be a part of the work. I wanted to help develop an actionable plan so people would be aware of what to look for and be able to ask, “Could this be sepsis?” The project included a video of me talking about my sepsis experience with Steven and other community outreach materials. (CAPS Note – included below.)

Since then, I’ve been involved with other projects, including CANDOR – Communication AND Optimal Resolution – as a family advisor and as an expert in process improvement. We are currently looking at TeleHealth, and the impact COVID has had on the delivery of care.

## **CAPS: What projects have you been involved in?**

**Steven:** I’ve worked with PCORI, Vizient, and SIDM on projects. At Georgetown, we re-wrote the Stroke and Transient Ischemic attack patient guide protocols and numerous hospital policies and procedures to ensure a patient focus. We’ve worked on tackling the Opioid Crisis and medication reconciliation. I think Georgetown showed a real commitment to including the patient voice when they asked me and others to provide design inputs as they broke ground on a new surgical pavilion. Bringing a patient perspective is crucial to improving patient outcomes. We worked on hospital design and looking at how design impacts outcomes. Something as simple as having phone charging stations in waiting rooms can make a difference.

Besides those I’ve already talked about at Georgetown, we’ve started a discussion series called “Hot Topics.” These quarterly events look at social factors in healthcare. This week we’ll be talking about diversity and inclusion. I’m excited to moderate this topic because we are having candid conversations about matters that concern healthcare providers and patients. There are a lot of talks now about disparities in care. The Covid-19 pandemic highlighted gaps in health care access and services. Inclusive means that persons don’t experience incremental inequity. When you repeatedly meet small barriers to care, you become disengaged. Incremental accumulation of micro disparities in care leads to a macro breakdown. If we just look at the global statistics on differential outcomes for different populations, we’re not going to be able to fix the problem. We need to break down and teach about the micro issues, too. The biggest issue is developing a culture of respect and inclusion.

## **CAPS: What would you recommend to persons who want to advocate for Quality and Safety?**

**Steven:** First, get involved. Recognize you have a voice. As a consumer people often feel they are more than just a customer—they feel empowered to make sure that their goods and services are correct every time. In medicine, we don't have the same feeling. YOU have a voice, and for the most part, Doctors want you to be active in your part of your care.

When Steven was in the hospital, I always went to rounds. Always! Except for one day when I asked when rounds were happening and found that they had already occurred. I started with the lowest level of the pecking order and asked each person in turn, "I always attend rounds; why would you not include me in rounds today?" When I finally got to Steven's attending physician, she apologized and agreed that I would always be included in rounds. These discussions were always cordial but direct and asserted my voice as a patient partner.

I didn't realize then that my insistence on being included was setting an example for other patients. When you're in the hospital for days or weeks as we can be with Steven, the other families become your family after visiting hours end. I recall there was a 19-year-old woman on our floor there with her child who had a transplant. I never saw her in rounds. I asked her why? She said, "I've never been asked." Now, this woman may not have looked like me; she may have been very young and may not have had the same level of insurance or background. Nonetheless, she deserved to be involved in her child's care. She started coming to rounds. She learned to say, "I don't understand," when Doctors described the plan for her child. She learned to ask for clarification over and over. The providers learned to make the medical jargon they used more understandable. A 19-year-old woman had a voice.

We need to invite everyone, regardless of their background, to have a voice.

**CAPS: What would you recommend healthcare systems do to improve Quality and Safety?**

**Steven:** Healthcare systems have to take calculated risk. That is hard to do, especially when Risk Management departments exist to insulate systems from risk.

The system needs to think outside the box. They need to find tactics and techniques to address problems. You can't see a problem as clearly from inside the box in which the problem was created. Having a PFAC and inviting persons from outside the box to address issues is one way to gain new perspectives and solutions to problems. Engage PFAC members beyond their regular group meetings and put community members on quality and safety committees.

Risk management feels concerns that patients might learn the system makes mistakes. Patients already know you make mistakes. Take the risk and don't just look at problems in a vacuum.

For me, going into a hospital remains a significant emotional event. That feeling is not the same for the people who work there. They need to include me and persons like me to gain a complete understanding of what happens in their facility.

My pastor often says, "How can you love the people if you don't know the people?" As I translate that to patient safety and quality, I say, "How can you improve patient care without including the patients?" Medicine has always been and will forever be a people business, and we must include patients if we seek to improve care delivery. You can't love the people if you don't know the people.

**CAPS: What are your future plans?**



**Steven:** I am currently anticipating continuing to advance in the Air Force. Following my military career, I want to work in the Healthcare Quality and Safety space. That is why I recently earned my Executive Masters degree in Executive Clinical, Quality, Safety, and Leadership from Georgetown University. I see myself working either with the Defense Health Agency or in the private sector.



When your vocation, what you are paid to do, and your advocacy, what you love to do, intersect, you find happiness and purpose. I often say, “Service is the price we pay for the space we occupy.” I want to continue to serve others by using my experience as a family member supporting my son’s patient journey combined with my military experience and formal education and training to push every health system towards patient-centered medicine with a focus on quality and safety.

**CAPS: Thank you, Lieutenant Colonel Steven Coffee.**

Here are some links to Lt. Colonel Coffee’s Patient Advocacy Work:

From SIDM: <https://youtu.be/jPMLx7hBU6k>

About the Care Relaxation Channel at the hospital (with cute footage of “Deuce”)

<https://youtu.be/kWaxcllBrEs>

What YOU Need to Know About Sepsis (with Armando Nahum)

<https://youtu.be/ydEJ-muOXnE>

Medstar Sepsis Prevention Education (includes video above)

[https://www.medstarhealth.org/mhs/about-medstar/quality-and-patient-](https://www.medstarhealth.org/mhs/about-medstar/quality-and-patient-safety/sepsis-prevention-education/)

[safety/sepsis-prevention-education/](https://www.medstarhealth.org/mhs/about-medstar/quality-and-patient-safety/sepsis-prevention-education/)

MedStar’s Multi Modal Sepsis Improvement project: <https://www.medstarhealth.org/mhri/focusblog/2019/05/31/multi-modal-sepsis-performance-improvement-initiative-outstanding-research-at-the-symposium/>

MedStar Health Sepsis  
Brochure – Page 1 & 2.



**Early Treatment Saves Lives**

You can help us help you. The sooner you or a family member gets treatment, the better.

- Look for signs of sepsis.
- Call your doctor or go to the emergency room.
- Ask, “Could this be sepsis?”

**THINK SEPSIS? Say Sepsis.**

For more information on sepsis, please scan the QR code with your smartphone, or visit the website below.

[MedStarHealth.org/Sepsis](https://www.MedStarHealth.org/Sepsis)

**MedStar Health**


10980 Grantchester Way  
Columbia, MD 21044

**SEPSIS: When an infection turns deadly**

Knowledge and Compassion  
**Focused on You**

### What is sepsis?

- Sepsis is a deadly response to an infection. Some call it blood-poisoning.
- It can kill you if you don't get treatment fast.
- Sepsis happens a lot.
  - It kills more people than breast cancer, AIDS, and prostate cancer combined.
- It's an emergency!



### Who is at risk for sepsis?

- People who have been in a hospital
- People with bad burns
- People who get infections easily
- Infants and children
- The elderly
- People with tubes or drains
- People with open sores or cuts

### How do I know if I have sepsis?

Symptoms may include:

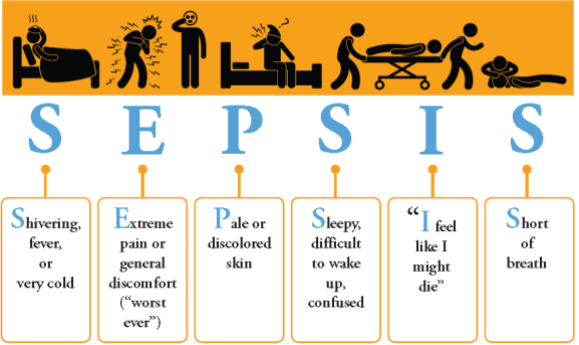
- Fever greater than 101° or shaking chills
- Very low temperature (less than 96.8°)
- Confusion or sleepiness
- Throwing up, diarrhea, unable to keep food and fluids down for more than 12 hours
- Fast heartbeat without exercising
- Hard to breathe, or breathing very fast or very slow

Report any symptoms to your doctor, who can determine if this is sepsis.

### What should I do if I think I have sepsis?

- Call your doctor **or** go to the emergency room.
- Ask, "Could this be sepsis?"

You can help us help you. The sooner you or a family member gets treatment, the better.



Infographic source: Centers for Disease Control and Prevention (CDC)

The videos in a series of COVID-19: Patients, Families and Providers in Conversation may be found at this link:

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

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 and be sure to hit subscribe **and** notify so you will know when a new, relevant video has been uploaded!



## COVID-19

Patients, Families and Providers  
*Three Voices, One Conversation*



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

## **\*From the Patient Safety Movement Foundation:**

We are calling for a Patient Safety Moonshot™ to eliminate the third leading cause of death in America. With your help, we can achieve the unachievable.

Please take a few minutes to watch [this video](#) and **join us**. Together, anything is possible.

## **\*From Pulse Center for Patient Safety Education & Advocacy:**

### **In the Age of COVID-19 Long Island Nonprofit Focuses Minds on Patients' Safety**

*by David Halperin*

*Decades-long fight to reduce harm from medical error and support patients and families.*

If COVID-19 has done anything positive, it is to focus some — not all — minds on the risks and pitfalls of medical care.

The sad stories of desperately sick people on ventilators, isolated from their families and unable to speak to doctors, are only the most visible tip of an iceberg that includes medication and diagnostic errors, mixed messages from health and government authorities, unreliable communication between patients and providers, and slipping hygiene standards, to name just a few.

This is hardly surprising: before the pandemic, medical error was listed as the third-highest cause of preventable deaths in the United States. It would be astonishing if patients' safety had not suffered under the multiple pressures of overcrowded hospitals, fearful and exhausted staff, and a new, highly unpredictable disease.

People are asking, "What can we do?" The answer for some is to follow at least the minimum safety guidelines agreed by most medical experts to be quite effective in preventing infection: masks, frequent hand-washing, social distancing and the like.

But according to Ilene Corina, President of Pulse Center for Patient Safety Education & Advocacy, people can do much more — not just to keep from getting COVID-19 — but to stay safer if any kind of medical care is needed.

#### **Taking responsibility**

"Some people seem fatalistic," she comments. "They say, 'If I get it, I get it; we all have to die of something.' But as we at Pulse Center for Patient Safety Education & Advocacy have been teaching for many years, there *are* things we can all do to at least improve our chances of a good outcome. We can't leave it all to the doctors and nurses: if we take some responsibility ourselves, we can make a difference."

Take responsibility? One might reasonably reply, “Are you kidding? I’m sick, I feel awful and I barely know what day it is — how can I take responsibility?” The answer, says Corina, is to prepare ahead of time. “It’s like a car seatbelt,” she points out. “You don’t put on your seatbelt *after* you see you’re going to crash. You’ve already done it, so it’s there to protect you.”

## **Pulse — Educating from the Ground Up**

Ilene Corina, herself a board-certified patient advocate, has been doing this for many years, so she’s “seen it all”. She never charges for her services at the bedside. Patient advocacy is also a profession, but Corina believes that with training, nearly anyone has the potential to support a family member or friend in this way. So for many years Pulse has offered in-person courses — [Family-Centered Patient Advocacy Training](#) — to individuals and groups on Long Island. COVID-19 has changed all that, and now training — and many other Pulse activities — have gone online via Zoom and other platforms. While that has some limitations, paradoxically it opens up the possibility of reaching a much greater audience with the patient safety message.

## **The TakeCHARGE Campaign: 5 Steps to Safer Health Care**

Pulse’s latest major project, launched in 2020 and continuing in 2021, is The [TakeCHARGE Campaign: 5 Steps to Safer Health Care](#). TakeCHARGE is a public awareness and motivational campaign to encourage everyone to take five relatively simple steps that can help improve their chances of a good outcome from medical care. Each can be linked directly with one of the risks to patients’ safety mentioned above.

1. **Complete your advance directives.** "Advance directives" is a general name for several kinds of documents you can sign to help ensure that your wishes about medical treatment are known and respected if you are unable to communicate for yourself. This is more important than ever in the age of COVID: when you’re on a ventilator, you can’t speak for yourself. How many out of those thousands of people in ICUs had not completed a Living Will or Healthcare Proxy document beforehand? Probably most, meaning they could not be part of their recovery. Even when the pandemic is over, advance directives will remain important. Forms for these common documents are easily found online.
2. Keep track of your **medical history and medications** and bring this information with you to every medical appointment. Rather like a resumé that summarizes your working experience for a prospective employer, a well-maintained medical history shows both you and your doctor at a glance what has been happening with your health over time. Many errors in medical decisions can be avoided with a personal medical history. This doesn’t have to be anything fancy: it’s enough to have a simple notebook with a dated list of every symptom, medical appointment, treatment or medication and their results. And you should share your list of medications with every provider: doctors, hospitals, nursing homes and any other healthcare providers.
3. Prepare a **list of questions and symptoms** before you visit your doctor or go for a procedure or to the hospital. If you’re young and healthy you may only see your doctor for an annual checkup, but even then, most of us will have a few questions. Don’t trust you’ll remember them in the provider’s office: write them down and bring them with you. Describe your symptoms accurately and objectively, don’t exaggerate or minimize them. Leave room in your notebook to write down the answers to your questions.
4. Help stop the spread of infections. **Ask caregivers to wash their hands** before touching you. Healthcare-associated infections (HAIs) are common: according to the latest (2018) data from the CDC (Centers for Disease Control), one in every 31 patients in the US became infected while under treatment. As we have been hearing since the COVID-19 pandemic began, thorough hand-washing is one of the best ways to avoid transmitting disease. But medical staff, under constant pressure of heavy caseloads and time, sometimes forget. Part of Pulse’s training is learning how to insist,



politely but firmly, that everyone who touches you washes in your presence. This is difficult for many of us, but it's worth learning how.

**5. Choose an advocate and be an advocate for someone else.** The time to choose your advocate is *before* you suffer sickness or injury. Sometimes your closest family-member isn't the best person to be your advocate: an advocate must be able to maintain calm focus and stay objective, which is not always easy for those nearest and dearest to you. The advocate's role is to support the patient in dozens of practical ways, from taking notes to sanitizing bed rails to organizing a schedule for visitors. These are things anyone can learn to do, with training from Pulse and the TakeCHARGE Campaign.

## In the Time of COVID

The TakeCHARGE Campaign was always planned as a partly online drive, and the novel coronavirus made that imperative. It is waged on several social media platforms — Facebook, Instagram, Twitter and LinkedIn — and via interactive Zoom presentations and YouTube videos. The Campaign laid out the basic ideas in March 2020, and then urged viewers and site visitors to take one of the 5 Steps each month.

Campaign Co-Director David Fielding says, ""When we started the campaign, we knew how important it was to share the 5 Steps with the public. With only a few volunteers and fewer resources, we were thrilled when our daily posts on social media grew by hundreds of followers each month from March to September. In 2021, we expect our reach to grow into the thousands and beyond!"

Hofstra University student interns were an important part of the campaign, contributing memes, ideas and a youthful perspective. Intern Abby Briggs went further, shooting an "[Ask Abby](#)" video series that explored the particular ways the 5 Steps apply to young people. "Everyone on our team has worked and continues to brainstorm the best ways to reach people," she says, "because when it comes down to it, that's what this is about—reaching as many people as we can and providing them with what they need to be well-prepared and informed patients."

The tight focus of the campaign and the simplicity of its message led The Joint Commission, the country's leading hospital-accrediting organization, to endorse it for their large staff, and to spread its message via their own [website](#). "It is unprecedented for The Joint Commission to support a particular independent health education campaign," says Corina. "It's a testament to the planning and hard work that the TakeCHARGE team put in over the first eight months of 2020, and we are very gratified that such a prestigious organization has lent us its approval in this way."

Corina adds, "Just as the Joint Commission spread the TakeCHARGE Campaign message to its ±1000 staff, all companies and businesses can follow that example and encourage their employees to join the campaign and do the 5 Steps. Not only will they be doing something good for their people, but it may help the bottom line, as safer health care can translate to fewer working days lost to sick-leave."

## What Next?

The TakeCHARGE Campaign continues and will ramp up its activities further in 2021. Says Corina: "People benefit from taking the 5 Steps at any time, but it's even more urgent now because this pandemic isn't going away any time soon. So please, visit [www.takecharge.care](http://www.takecharge.care), find the answers to your questions, and become part of the campaign by taking the 5 Steps to Safer Health Care yourself and helping your family do the same."

# Consumers Advancing Patient Safety

January 2021



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