

November 2019

Thankful for Patient Safety



In the United States and many other Northern Hemisphere countries, we celebrate Thanksgiving during the autumn. Of all the US holidays, this one offers the most universally celebrated traditions of family and gratitude rituals. This year, I am particularly thankful for Patient Safety and the combined work of Patient and Family Advocates all over the world. And, I am thankful for clinicians who work to provide safe, quality care.

Just a few days ago a dear friend, who never asks for help, asked for a ride to the Emergency Room. My friend ended up needing intense intervention and surgery. I saw excellent, safe care. I saw careful and thoughtful shared decision making. I did have to mention that someone

who had lost a tremendous amount of blood was probably a falls risk – but other than making sure my friend had those precautions, I felt very positive about my friend's experience and grateful a full recovery can be achieved.

Last July while I was sitting in a Sunday School class at my Church, the volunteer teacher leaned over the podium and said, "I think I'm having a heart attack!" My fellow congregants sprang into action with several men carrying the teacher out of the room to the parking lot. Another friend called emergency services. My Sunday School Teacher was whisked away to the hospital and was stabilized and received excellent cardiac care. He had a contained aneurysm that was surgically repaired a few days later, along with a quadruple bypass. His surgeon, who had been teaching his congregation the same Sunday School lesson at the same time, said that my friend and neighbor could have died right on the podium. A series of things went right, and my now former Sunday School teacher will enjoy this Thanksgiving with his wife and children and grandchildren.

As I write this, two families I know are thanking the pharmaceutical industry. I know we sometimes feel upset at big pharma, and rightly so. My friends, however, have children with Spinal Muscular Atrophy and Cystic Fibrosis. My friend with Spinal Muscular Atrophy is now ten years old. His Mom was told he would not live to be two years old. He has been receiving the new medication, Spinraza, for over a year. He has slowly been able to move limbs he could not move before. His family will be giving thanks for the researchers who developed this miracle medicine that will hopefully help this young man achieve more years and fewer hospitalizations. My friend with Cystic Fibrosis is a young adult now. He will be taking the just recently FDA approved medicine, Trikafta. This medication promises to significantly improve his lung and digestive functions. His family and friends are excited and will be giving thanks for all the work that has gone into this medicine.

In this issue, CAPS talks to Rosie Bartel, reviews the *Health Equity and YOU* webinar, shares information about the upcoming *Honoring Faith and Holiday Traditions in Healthcare Settings* Webinar and reviews the new book <u>Birds Eye View</u>. Thank **you** for being a part of the CAPS community. **-Lisa Morrise**

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Consumer Advocacy Panel (CAPS CAP) Interview – Rosie Bartel

CAPS CAP has over thirty active Patient Advocates from all over the United States. We hope to expand our CAP to international members in 2020! Each month we will feature an interview with one of our Panelists. (Picture below: Rosie Bartel and her husband, David Bartel.)



Rosie Bartel had total knee joint replacement surgery over ten years ago. During that surgery she contracted a MRSA infection. *CAPS: When did you start your advocacy?*

Rosie: Eight years ago, about six months before I had my leg amputation.

CAPS: How has your advocacy evolved over the years? ROSIE: I started by telling my story at the hospital where I contracted MRSA. My Infectious Disease Doctor invited me to share my story. Then, the Institute of Healthcare Improvement invited me to do a video sharing my story. Over the years, I've learned how to adapt how I share my story to the audience that I am speaking to. I talk about many issues I've encountered as a patient now. I've talked to groups about shift change, rounding, sepsis and hand washing. A few facilities have started "What would Rosie do," campaigns. They actually have signs around the facility reminding staff to think of me as a means to remind them

to follow infection prevention and patient safety protocols (such as handwashing). I also advocate for accessibility issues and have started to talk about electronic medical records and environmental services issues. I want to take my story from a story that touches hearts to one that touches heads, too. I want the story to motivate persons to keep patients safe.

CAPS: What projects have you been involved in? (Rosie has a list a page long ... the highlights are:) Rosie: One project I've been involved in recently was to work with a medical equipment company. They manufacture surgical staples and other wound closure materials. They now have a, "What would Rosie do," campaign. Hand washing was the first project I was involved in. My local hospital posted, "Think Rosie," signs in all the rooms. They reminded staff how important hand hygiene is and how infection spread can impact a patient's life and their families. I'm working right now with the Electronic Medical Provider, EPIC. I am talking to EPIC about accessibility on their campus and their patient portal, My Chart, as well as I spoke at their conference. EPIC is located in Wisconsin, close to where I live.

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

Rosie: I think you have to be able to put your anger aside. You have to be able to tell your story in a way that touches hearts with compassion and empathy. You also have to think about what you can do to effect change with your patient experience.

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CAPS: What would you recommend healthcare systems do to improve Quality & Safety.

Rosie: Everyone needs to be empowered to speak up if they think something isn't safe. Housekeeping and engineering too! Everyone is on the Quality and Safety team. Healthcare is not just what happens to you – but also what happens around you. Clean rooms, where instruments are sterilized, for example, may not really be that clean! But making it really a clean clean room can make all the difference.

CAPS: What are your future plans?

Rosie: Well, I turned seventy this year. I hope to still be doing what I'm doing until I am eighty or more! Being an advocate helps me feel young. Also, I feel like I am doing God's work when I help people (I will never meet) avoid ever contracting a MRSA infection like I have experienced.

CAPS: Thank you Rosie, for your advocacy!

reCAPs: Healthcare Equity and You Webinar

The first Webinar in the CAPS Perspectives Series featured Erica Gollett-Steed, MBA and Ronald Wyatt, MD sharing their insights into how you as a patient or clinician can achieve health equity.

Steed shares her impactful story of inequity, where implicit bias in her care led to long-term injury to her then newborn, now teenage, son. Steed encourages persons to be the "CEO of our temples – bodies," by:

- Having awareness of your personal Assumptions (Think)
- Avoiding Shortcuts (Act)
- Reflecting on Actions (Study)

Dr. Wyatt shared data that documents the outcomes of inequity and the biases that exist among some providers. Dr Wyatt:

- 1. Discusses Equity and Patient Safety
- 2. Reviews the multiple determinants of health
- 3. Recommends an Equity strategy

Listen to this Webinar, that CAPS Community Advisory Panel member Tara Bristol Rouse called an, "Amazing opportunity to hear from two transformational leaders re: the promotion of equity in healthcare..."

To watch the complete webinar, please go to: Healthcare Equity and You CAPS Webinar

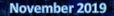


Ron Wyatt, MD, Chief Quality Officer at Cook County Health, one of the largest public health systems in the USA.



Erica Gollett-Steed, MBA, Patient Advocate, Former Manager, Patient and Family Centered Care, Georgia Health System.







"I wrote this book to explain how it feels to be a cancer patient and the mom of a child with a disability. In my experience, empathy has been sacrificed by health care's obsession with efficiency. More compassion is what's desperately needed for us all - patients, families, students, staff and physicians alike."

-**Sue Robins**, Mom to a child with Down's Syndrome and breast cancer survivor.

If you have a book you would like to review for the CAPS Book Club, please let contact us!

CAPS Book Club

Guest review by Isabel Jordan of <u>Bird's Eye View: A Story of Life Lived in Healthcare</u> by Sue Robins. This review first appeared as a Twitter thread by @seastarbatita.



"So, a couple of days ago, I finished reading Sue Robins' book, <u>Bird's Eye View</u>. In it, through a series of personal and profoundly insightful essays, Sue talks about compassion in health care – where she's found it, and importantly, where it's been missing.

"Sue speaks from her experience as a caregiver – a mom who wants her disabled son to thrive on his own terms, who sees societal biases against disabled people reflected in health care as well.

"Sue speaks from her perspective as a patient, looking for care in health care and feeling adrift. As a parent and as a disabled woman, this book spoke to me. Sue doesn't presume to speak for others. Instead, she challenges the world of health care to do better, to be better, by questioning why we need to continue doing things as they have been done.

"I encourage my followers in health care, regardless of your role, to read this book. But don't just read it, take up the challenge that Sue Robins gives to you as a gift. If you're a caregiver or a patient, as I am, you may find solace and power in Sue's words."

Isabel Jordan is a founding member and Chair of the Rare Disease Foundation and a patient partner for SKIP, a knowledge mobilization network that seeks to bridge the gap between treatment practices and evidence-based solutions for children's pain in Canadian health institutions. Isabel is the mother of a young man living with a rare disease and has become a strong advocate for patient partnership in research. She's been interviewed on radio, written on patient engagement, co-authored Patients Included charters, is a member of numerous health research teams, and has spoken at national and international conferences about patient partnership.



Webinar Planned:

Rachel Wiessburg, MA and The Spiritual Services Department at Children's Mercy Kansas City Will Address Honoring Faith and Holiday Traditions in Healthcare Settings December 12, 2019 – Noon Central Time Please join my meeting from your computer, tablet or smartphone. https://global.gotomeeting.com/join/761745677 You can also dial in using your phone. United States: ±1 (224) 501-3412

Access Code: 761-745-677

New to GoToMeeting? Get the app now and be ready when your first meeting starts: https://global.gotomeeting.com/install/761745677

www.PatientSafety.org

For the last several months, a team from CAPS has been working on improving our web site. Our goal is to both have a place you can quickly look for news and information about CAPS and find resources for various patient safety topics. The construction dust has settled a little bit and the new website is now up. Please feel free to take a tour.

The resources page remains under construction at this time. We hope to provide you with links to a number of helpful videos, papers and information about Patient and Family Engagement, Quality and Safety practices and education about how to develop patient safety legislation at the State level.

You will also find a form on the Contact page where you may leave feedback. We want to hear from you!

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Facebook Page for CAPS

Have you "Liked" the Consumers Advancing Patient Safety Facebook page? We try to share articles and information specific to Patient Quality and Safety. We also try to only post once a every day or two, so your feed will not be overwhelmed if you choose to follow our posts.

Do you have information for the CAPS Newsletter?

Please send us information about what you are doing to Advance Patient Safety. Send it to capspatientsafety@gmail.com

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