

## Focus on Caregivers



I saw a comment from Sarah K from Canada on social media recently, “Often becoming someone’s caregiver is not a choice nor does it come with much notice. Caregivers need to be supported!” I agree! Thankfully, this is [National Caregiver’s Month](#) in the USA. Other countries also honor caregivers. Unfortunately, support for caregivers varies widely.

I balked at having my two-year-old sent home from the hospital after a one-night trial on CPAP. Skyler had been previously trached and decannulated but continued to experience significant airway obstruction during sleep. I tried every communication technique I knew to convince the resident doctor that I really needed more support before taking my child home as nurses looked on wide-eyed. The resident would not budge. I would, he suggested, receive training from homecare staff. Having already had to figure out complex equipment on my own, I knew that was unlikely. Finally, the attending physician wandered by. I literally reached out and grabbed his lab coat shoulder and dragged him into my conversation with the resident. The attending’s response was, “We never send them home after one night. We need more time to make sure the settings are correct.”

I was grateful for another night to learn equipment but notice that my concerns were not the reason the attending overruled the effort to discharge my kiddo. In other situations, I must say the hospital provided more support, with specific trach training and training around dealing with tube feedings. But often I was sent home feeling like I was swimming upstream in the technical caregiving river.

Over twenty years later things hadn’t changed much. After Skyler’s third jaw advancement surgery, we were sent home, jaw wired shut, with an array of ten medications to deliver via a nasal jejunum tube. Only a few of those meds were available in liquid form. Several required me to open a capsule and dissolve the contents in liquid. Still others required that I crush the tablet and dissolve the resulting powder. Some medicines were to be given twice a day, some three times a day, others every so many hours and still others as needed. To add to that, the nasal jejunum tube meant that only small quantities could be delivered at a time. I could not group the medicines all together as I could (and one time did) cause “dumping syndrome.” I felt overwhelmed as I struggled to set up a spreadsheet in Excel to help schedule everything. Every provider from the hospital to homecare went over the list of medicines with me, their version of medication reconciliation. Not one offered help on HOW to go about organizing and administering the medicine.

That situation and others made me particularly interested in the work of patient-centered medication management. Patients need to know not just what they’re taking, why they’re taking it, what they have been dispensed looks like and what the side effects may be. They also need to know HOW to manage their medicine. What should they take, when? What system will they have to actually manage all the meds, for example a pill box divided by daypart? And, oh by the way, working with patients closely I have come to find out they do not

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understand the role, education or support the pharmacist can provide. So, when asked, “Would you like to speak to the pharmacist,” many patients don’t even know what they are being asked.

Recently CAPS Board president and founder of Mothers Against Medical Error, Helen Haskell, participated in and I co-chaired the National Quality Forum Action Team on Patient Centered Medication Management. We joined over twenty clinicians and several patient advocates in exploring how to improve. In meetings over six months, the Action Team developed four recommendations. I’ve outlined those on pp. 6-7 below and linked to the accompanying brief. I appreciate NQF’s work in this area and hope more caregivers feel supported in the roles thrust upon them. -**Lisa Morrise** ([lisa.morrise@gmail.com](mailto:lisa.morrise@gmail.com))

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## CAPS Consumer Advisory Panel Profile



### **Susan (Brown) Buchanan, MPH**

*Susan Buchanan is Director of Federal Health Solutions at Telligen in West Des Moines, Iowa where she has worked for 24 years. In her role, she implements new operational models and IT systems for Medicare. Susan is also an adjunct professor and board member of a local college. A mother of three adult children, she serves as legal guardian and advocate for the younger two with Fragile X Syndrome, a genetic intellectual disability. Susan is involved in numerous advocacy efforts and is a consultant at her church for families with newly diagnosed special conditions.*

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

**Susan:** I really started advocating for my children and my family shortly after we found out about a genetic condition in our family twenty years ago. I have three grown children. My youngest two inherited a DNA-based condition called Fragile X Syndrome.

Fragile X is not routinely tested for in prenatal exams or in infants. Unbeknownst to us, the genetic issue had been in my family for many generations but had been asymptomatic or not properly diagnosed. Eventually, though, it will impact someone’s children. The genetic anomaly has a fifty percent pass-along rate. My oldest son did not have it. My daughter was eighteen months old when her younger brother was born so even then we didn’t realize it was in our family. Both my daughter and youngest son are impacted, although my youngest has the most severe impact. My son was not diagnosed until age two. We took him to the Mayo Clinic for Global Developmental Delay, and they identified what was causing his developmental issues. At that point we realized my daughter’s differences in development, while not as severe, were also the result of Fragile X syndrome.

I got involved with the [National Fragile X Foundation](#). They asked me to support them through a Congressional advocacy day. I was able to talk to my Congressional delegation about the need for interventions like early therapies, school-based services, respite care and the importance of our area education agency. We know that the earlier children receive services the better their long term outcomes will be.



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

**Susan:** My advocacy really revolved around my children’s needs. I helped start a local nonprofit called Let’s Soar Together. We provided networking for parents of children with special needs. We also worked on projects like swings that accommodate special needs students at local elementary school playgrounds.

I continued to volunteer both nationally and locally to support Fragile X advocacy. Until the children were 21, they had a lot of the structure and support they needed through the school system. They had a routine and were taken into the community. We had respite after school. Then, at 21, we had to leave school and I had to navigate my children’s interventions entirely on my own. The transition from child to adult services is extremely difficult. We lost teachers and therapists, as well as the networking with the other parents. So, the last time I talked to Congress, I was talking about the understaffed adult services, lack of housing and the challenge of waiting lists for services.

My two younger kids cannot live on their own. There is not enough funding through supports available to them to pay for 1:1 staffing. They need to be in a group living situation. Daytime rehab programs are lacking. There were no open housing spots available in our local community.

I ended up turning my own home into a group home so my youngest, nonverbal son would have a place to live. I chose to move out and purchase another home versus trying to transition Reece due to the lack of options for him. The home – that I still own – now serves 4 young men with intellectual disabilities and is staffed by an outside agency. My daughter lives with a family who receives funds for providing her the support she needs in a “host home” setting.



Jessica, 24  
Measured IQ= 40  
Works at HyVee 25-30 hours  
Lives in Mosaic “Host Home”  
SSDI & Medicare due to disability



Reece, 22  
Measured IQ = 9, Non-Verbal  
Lives in men’s group home  
History of seizures  
Intellectual Disability Waiver - Iowa  
Medicaid, SSI  
Toilet trained at 19

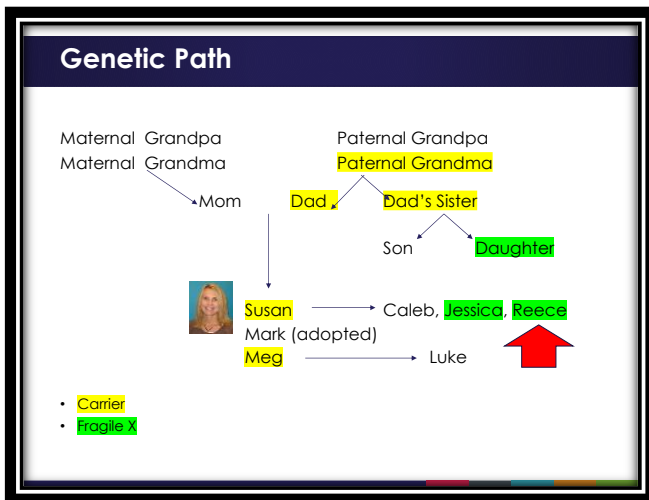
Every fall, I take the kids and my Dad, who is a physician, to talk to the freshman medical school class at the University of Iowa. We speak to about 220 physicians in training. We basically serve as a genetics case study for them. I approach the presentation from the perspective of what I want health care professionals to know to improve the partnership with patients and caregivers. We talk about how the providers can support parents of special needs and the impact the Fragile X diagnosis has had on our lives.

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

**Susan:** I was asked to participate in the CMS Transforming Clinical Practice Initiative (TCPI) from the patient or family caregiver perspective. In my work life, I am a director for Telligen, a company that works with federal, state, and private partners to work on healthcare solutions and provide healthcare expertise. But in my TCPI work, I was considered faculty outside of my regular “day job,” sharing my perspective as a caregiver to children with complex needs.

I led a TCPI work group that developed a compendium of patient and family engagement resources. (Various organizations have placed the compendium on the internet. For example, it may be found [here](#).) This was a volunteer task.

My family has participated in several research studies. We are an interesting case study because the Fragile X syndrome impacts both a boy and a girl in our family, my sister and I are both carriers, and we inherited the gene from my father who is also a carrier and a physician. My sister found out she was a carrier prior to having children, therefore opted for special fertility screening so her son would not inherit Fragile X.



I have shared my story with different medical newsletters and accept various speaking opportunities at churches, philanthropic organizations, and health care settings.

I was a big advocate for telehealth before COVID. For a child with intellectual disability, going into an office should not be mandated. I used to drive two hours to a center for excellence for children with disabilities. I asked to do the visit by telehealth and was told, “Oh, we don’t do that.” Now they do! My son, for example, can have medication management appointments via telehealth, saving us an in-person visit and greatly reducing the associated stress and anxiety.

When we do go in, our provider is sensitive to my son’s tactile issues, including his aversion to being touched. They perform weight checks and blood pressure and other clinical assessments that involve touching, but my son’s physician allows him to have these assessments outside of the exam room and minimize his anxiety through a careful, thoughtful approach for each contact.

I’ve advocated for cluster visits, where a person with complex issues is seen by as many providers as possible in one visit to a facility. This not only lessens the time spent going back and forth to appointments. It also reduces the stress on the person being seen, as their normal routine is disrupted less often.

**CAPS: What would you recommend to persons who want to advocate for quality and safety?**

**Susan:** Advocacy is something that occurs at all levels and doesn’t always need to be a formal, structured approach. You can advocate as a caregiver at a doctor appointment all the way up to Congress. Some settings may be in a large auditorium and others may be in a small outpatient surgery exam room discussing sedation. Anyone can be an advocate. It can be scary, but you can do it if you are transparent, positive, and clear with your messaging.

Take the time to really know what you're asking for. What are you really trying to accomplish with your story, for example. A story alone, without being connected to an action you are requesting, can be viewed as moving, but not impactful. If you have just fifteen minutes of facetime with a leader like a Congressman or a healthcare system administrator:

- Lead with the heart, be personal and transparent
- Make requests that are focused and practical.

### **CAPS: What would you recommend to health care systems to improve quality and safety?**

**Susan:** They need to become like other industries that are customer-focused. Healthcare tends to be built around the health care company's and provider's needs. They need to learn from other industries how to design services to meet customers' needs.

As we've messaged in patient and family engagement work, the patient and caregiver should be viewed as a necessary part of the care team. We need each other to have the best possible outcomes. My kids' providers need me, and I need them. It's a partnership with equal spots at the table. In essence, we all share in the decision making to achieve the best outcome.

Understand the whole person to the extent possible over time. Being an empathetic human being goes a long way. We are so much more than a genetic condition. A little asking, "How are you doing," or "what does a good day look like in your family" goes a long way. Don't lose the human aspect in accommodating technology. The simpler things are, the better.

And speaking of technology, patients don't need 15 different portals or logins! We need to simplify patient access to their records, not make it complicated.

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

**Susan:** I plan to continue what I've been doing and adapt to the different phases of my family's experience. I would like to help other families navigate the transition to adult services and also hope to have more PFE opportunities through my regular job as well.

I just got both of my children with Fragile X syndrome in a good living situation. I want to support their health so that they age well. That means supervising their nutrition and exercise options. My overarching goal is stability. They will most likely outlive me and that is something that I also need to prepare for.

**Thanks, Susan!** Contact Susan Buchanan at [sbuchanan@telligen.com](mailto:sbuchanan@telligen.com).

#### "My Wish List"

- Get to know the whole person
- View me as part of the care team who can "share in decision making"
- Waiting is difficult, being touched is difficult. Be aware and be flexible.
- The simpler, the better





## ZOOMING for you in DECEMBER: Restarting and Energizing PFACs - Easy to Implement How-To Lists

Brought to you by:

*Consumers Advancing Patient Safety (CAPS) and Healthcare and Patient Partnership Institute (H2Pi).*

### ***“Celebrating / Recognizing and Honoring PFAC Members”***

**You are invited to a Zoom meeting.**

**When: Dec 14, 2021, 02:00 PM Mountain Time (US and Canada)**

**Register in advance for this meeting:**

<https://us02web.zoom.us/join/98123456789>

**After registering, you will receive a confirmation email containing information about joining the meeting.**

- The second Tuesday of each month continuing with the meeting on **November 9** and running into 2022
- Each meeting will be held at 4:00pm Eastern / 3:00pm Central / 2:00pm Mountain / 1:00pm Pacific time
- **The Zoom meeting link is above. Please register in advance to reserve your space.**
- Each meeting will last just one-half hour
- Each meeting will feature practical lists of “how-to” implement best practices for Patient and Family Advisory Councils (PFACS)
- Member experts from Advisory Councils will offer their stories of how their facility implemented best practices
- All sessions will be recorded and will be available on the [CAPS YouTube Channel](#)
- Topics covered will include:
  - Meeting remotely – available now on the CAPS YouTube Channel
  - Recruiting patients for your PFAC, January 11, **2022**
  - Building and using an agenda – available on the CAPS YouTube Channel
  - Recruiting staff for your PFAC
  - Facilitating the meeting – available on the CAPS YouTube Channel
  - Diversity and inclusion
  - **Celebrating / recognizing and honoring PFAC members** – December 14, 2021
  - Training in patient safety terminology for PFACs
  - Choosing PFAC discussion topics

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

As noted above, CAPS participated in the National Quality Forum Action Team on Person Centered Medication Management. The Capstone webinar for the event may be seen now on YouTube [here](#).

The Action Team developed four recommendations. To support the improvements of person-centered medication safety, the Action Team recommended that healthcare organizations, community stakeholders, and patients, families, and caregivers partner together to:



- Build an accurate, beneficial, and comprehensive medication list
- Provide clear, readable, and understandable medication instructions
- Educate and empower patients and caregivers to be partners in their care
- Prioritize and invest in person-centered medication safety

You may download the entire Issue Brief here: [Project Materials NQF Action Team: Person-Centered Medication Safety](#).

One aspect of the six-month long effort that was interesting was that at each meeting, payment models were discussed as a barrier to achieving person-centered medication safety. CAPS colleague, Brian Isetts, shared his thoughts about this issue after we mentioned recently that pets seemed to receive better follow-on care than some humans. Dr. Isetts agreed that I could share his thoughts with you. **-Lisa Morrise**

## Thoughts from a Pharmacist

Fee-for-service financing is inherently flawed as a disincentive to patient-centered care. First of all, there is limited fee-for-service insurance financing for pets, and it's not really based on doing more procedures on animals.

And second - When Medicare was enacted in 1965, medical professionals fought this landmark legislative as being "socialized medicine," and the trade-off was to establish a reimbursement system whereby claims would be submitted and paid on a piecemeal basis for most all services and procedures (an inherent incentive to do more things TO patients rather than FOR patients). However, it was generally recognized at that time, that fee-for-service was inherently flawed, and at some point, in time we would need to revise this reimbursement system so as not to incentivize more services and procedures.

Well, the good news is that we (collectively across stakeholders) have been trying hard to overcome the nearly immovable force of nature of fee-for-service, with value-based or outcomes based reimbursement (e.g., ACO's, Alternative Payment Models, etc.) where providers get paid when patients do better. Isn't this the best thing since sliced bread, Mom, and apple pie?!? So why have we been working so hard over the past 15-20 years to try and change this healthcare reimbursement system with so little progress?

Ultimately, the best way to decrease this reliance on fee-for-service payments may have to come from Person and Family Engagement organizations (like CAPS) and thousands of us who step up en masse and say, "We're mad as heck, and we're not going to take it anymore!"

If you think this short story novel is of interest to your readers, please do feel free to share and disseminate liberally.

When we stand together, we can overcome all odds.

**-Brian Isetts, PhD, BCPS, FAPhA, Professor, Department of Pharmaceutical Care & Health Systems, University of Minnesota**



## Thoughts on Fear from Rosie Bartel

Our colleague, Rosie Bartel, recently contributed as a co-author on an article published in the Patient Experience Journal. From the abstract: “This article is a narrative of one patient’s (Rosie’s) experience during COVID-19. As a non-COVID patient, she shares her personal fears, the fears of others in her family and the fears of the healthcare professionals. These fears have made navigating the healthcare systems stressful for patients but also caused patients to avoid them completely. In some cases, this avoidance led to delayed diagnosis, missed diagnosis and death. When healthcare providers guide patients through the process of seeking in-person healthcare, the outcomes were more positive for everyone involved but especially for the patients and their care partners. The patient’s voice is needed to help healthcare professionals understand their fears and how to provide the best healthcare for all.” Find the article at [this link to the Patient Experience Journal](#).

## Graphics Garden

### 10 WAYS TO APPLY SELF CARE FOR WHEN YOU'RE NOT FEELING GREAT

1. Stay hydrated and make sure you drink plenty of fluids
2. Plan your day to make sure you can take lots of short breaks
3. Take a nap in the early afternoon if you start to feel really tired
4. Ask for support from other people so you can reduce your workload a little if it'll help speed up your recovery
5. Keep a close check on changes to your physical state. If you're starting to get worse, stop work and get some rest
6. Prioritise your recovery from the illness. Put this ahead of other things
7. Be realistic with your expectations of yourself. Understand that you're ill, accept that you're not at full capacity and set sensible expectations
8. Don't go to work and spread your bug around. You being ill is not great, lots more people getting ill is worse

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Mental Health @ Work

### DOMO Data Never Sleeps 9.0

How much data is generated every minute?

The 2020 pandemic upended everything, from how we engage with each other to how we engage with brands and the digital world. At the same time, it transformed how we eat, how we work and how we entertain ourselves. Data never sleeps and it shows no signs of slowing down. In our 9th edition of the "Data Never Sleeps" infographic, we bring you a glimpse of how much data is created every digital minute in our increasingly data-driven world.

Platform	Activity	Value
INSTAGRAM	USERS SHARE	65k PHOTOS
FACEBOOK	USERS SHARE	240k PHOTOS
FACEBOOK	LIVE RECEIVES	44M VIEWS
YOUTUBE	USERS STREAM	694k HOURS
NETFLIX	USERS STREAM	452k HOURS
TEAMS	CONNECTS	100k USERS
ZOOM	HOSTS	856 MINUTES OF WEBINARS
SLACK	USERS SEND	148k MESSAGES
VENMO	USERS SEND	\$304k
INSTACART	USERS SPEND	\$67k
TIKTOK	USERS WATCH	167M VIDEOS
GOOGLE	CONDUCTS	5.7M SEARCHES
DISCORD	USERS SEND	668k MESSAGES
DISCORD	PEOPLE SEND AN	12M MESSAGE
CLUBHOUSE	CREATES	208 ROOMS
SNAPCHAT	USERS SEND	2M SNAPCHATS
AMAZON	CUSTOMERS SPEND	\$283k
AMAZON	PEOPLE SHOP	6M ONLINE
STRAVA	ATHLETES SHARE	1.5k ACTIVITIES

EVERY 1 MINUTE OF THE DAY PRESENTED BY DOMO

As of July 2021, the internet reaches 65% of the world's population and now represents 5.17 billion people—a 10% increase from January 2021. Of this total, 92.6 percent accessed the internet via mobile devices. According to Statista, the total amount of data consumed globally in 2021 was 79 zettabytes, an annual number projected to grow to over 180 zettabytes by 2025.

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#### Global Internet Population Growth (IN BILLIONS)

2016	2018	2020	2021
3.6	4.3	4.8	5.2

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#### 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](mailto:capspatientsafety@gmail.com)

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