



A COVID Information Conversation

Covid-19 claimed another important person in the medical field, Takuo Aoyagi of Japan. You may not be familiar with Dr. Aoyagi. You most likely know his work. Dr. Aoyagi was instrumental in the development of the pulse oximeter. Read the New York Times article about Dr. Aoyagi [here](#).

As a carer, you may, like me, have a love-hate relationship with the pulse ox. First my oldest child, a preemie, lived with a probe attached to his foot, reading the oxygenation of his hemoglobin by detecting the concentration of a specific light wave form. That experience lasted about five months and then on and off for seven years.

Then my daughter was born unable to breathe due to an upper airway obstruction. The pulse ox let us know when that airway had collapsed. Respirations were a lagging indicator, as the effort to breathe continued even when little or no air was exchanged. I read all the literature that accompanied every piece of medical equipment that decorated the nursery. I was especially interested in the spectrophotometry of the pulse oximeter, because way back in college I had done my Honors Biology Thesis on the color wavelengths of leaves.

One thing we all grapple with the current Pandemic is information overload. Getting up to speed understanding the ins and outs of caring for a COVID patient or learning how to maintain a safe environment can be hard. We turn to the Infectious Disease specialists, because they already have a background with issues like R0 factors and droplet versus aerosol transmission. We turn to ICU specialists who routinely deal with isolation protocols.

You know who else knows about isolation protocols? Patients and Caregivers. Ask a Cystic Fibrosis patient how long PPE lasts and how it is used in the first several days of their regular two-week tune-ups in-patient in the hospital. Ask an oncology patient about social distancing during chemotherapy treatment. Ask a transplant patient about issues with immunity. Ask the parent of a medically fragile child about the horror of flu season, the sign on the door limiting visitors, their home-school and job routine and their lifetime supply of hand washing soap.

I've seen many persons with no scientific or medical background learn amazing things about their or a loved one's medical condition. Most importantly, they know how living with the disease or medical situation feels. They know the impact on their lives. They know how some simple actions on the part of providers may make a difference. They know how important a support system may be. They may feel left out of the current COVID-19 discussions of quality and safety improvement.

CAPS will be collaborating with two other patient advocacy groups, Project Patient Care and H2Pi in bringing you a You Tube series: **COVID-19: Patients, Families and Providers. Three Voices, One Conversation.** The series will include collaborative discussions about hospitalization, congregate living, post COVID care, Elective Surgery, SDOH, TeleHealth, EOL and Advance Directives, PFAC engagement, and more. The series will be available on CAPS You Tube channel and we will send you a link. I hope you find this information useful. Please share with us what you are doing to have inclusive conversations.

-Lisa Morrise

In this Newsletter, read on for:

- Follow-up information from Rachel Weissburg, sharing her brother's COVID-19 experience.
- An interview with Patient Advocate, Diann Folkersen.
- A list of resources you may find useful in the current COVID-19 situation, and more.

Another Patient Perspective - CAPS Programs, Subject Matter Expert, Rachel Weissburg, MS



A month ago, I wrote in this newsletter that I'd just learned my brother had COVID-19. When I looked back at what I'd written, it seemed like a lot longer than a month, and I wanted to share what it's been like to be a family member of someone struggling to fight and recover from this strange and persistent disease. I'm normally "the patient" in my family, so it's been hard watching someone I care about suffer, especially since he's in a different state than I'm in (I live in California - Josh is in Colorado). I don't want to tell Josh's story for him - he actually does that in a [blog entry](#). But I do want to share some of the things my family has learned since he first suspected he had COVID, which unfortunately was on his birthday, March 28.

The main thing that's been apparent is that every time we think we've got this virus "beat" it rears its ugly head again in some slightly different manifestation and says, "Oh no, I'm still here!" We're going on week 6 now, and Josh is quite sick. On the other hand, he has days when he feels well enough to take not-too-strenuous hikes, mow the lawn, go to the grocery store, and cook. So it's really up and down, which is a theme we're hearing from a lot of COVID patients.

Related to the above, symptoms can really vary from person to person. Josh has rarely had a fever, and only began to cough about three or four weeks in. The main, persistent symptom that he had from the get go was difficulty in breathing. He describes it as feeling as if he has a load of bricks sitting on his chest. It's not really that he can't breathe - because he can - he doesn't have pneumonia (thank goodness). But, it hurts to breathe, and it's not easy. The weight sometimes lifts, and it feels easier, but then it will return. If you did a line graph of the population based on health, Josh is one of those crazy athletic outliers who skews the data because he thinks climbing a mountain before breakfast is completely normal. So it's definitely NOT normal for him to struggle to breathe. Unlike me, he's never had a history of asthma.



The other big thing we've learned through this experience (and I'm sure this will come as no surprise to you) is how unavailable testing is. Beyond that - we've discovered how unprepared our health system is to collect information about symptomatic patients so that when testing is available, providers know who to call. Josh has never been tested (he's asked repeatedly and none of his doctors have information about testing in the Boulder community where he lives) - so technically we don't know he ever had COVID. But of the half dozen people I know among my friends both in the States and in other countries who've had it, none of them have been tested, so I think it's safe to say the majority of the population who is getting this virus is not getting documented. And now of course we have two tests - the diagnostic and the antibody test. The good news is that the antibody test is now available in Boulder and Josh's doctors are arranging a test for him. So within a week or so we should have the first actual data. This is really exciting because for any patient who's had COVID and has antibodies, there's a huge need for plasma, and the Red Cross, the Mayo Clinic, and the FDA are all coordinating to collect it. You can go to any of their websites for more information about how to donate.

Emotionally, one of the most difficult parts of COVID is the isolation. Josh lives alone, and although he had a friend helping to take care of him for the first part of his illness (who also had COVID symptoms, so it worked out), he's dealt with a lot of this by himself. My family is all spread out - California, Colorado, New York - so there's a lot of FaceTime-ing and texting and phone calls. We've gotten good at sharing information, care packages, and my 4 year old nephew dresses up in his doctor outfit so that he can "make Uncle Josh feel better over FaceTime", which of course helps everyone feel better. But it's a long road and we're still traveling it.

For anyone reading this who's sick or comforting a patient, we're all in this together. One day at a time. **-RW**

Rachel Weissburg holds a Master's Degree in Organizational Management from the George Washington University and is certified through the GW School of Medicine in Patient Navigation. She is currently a Patient and Family Advisor at her local Sutter Health hospital in Northern California, where she represents her own patient perspective as someone with one disease and two chronic conditions. She writes about these experiences in her blog, sleeplikeababytonight.com.

Consumer Advocacy Panel (CAPS CAP) Interview – Diann Folkersen



Diann Folkersen has been quietly impactful in advocating for patient quality and safety in Utah, currently with the Comagine Health PFAC. This is her story:

CAPS: When did you start your advocacy?

Diann: My advocacy really started with my PTA and Girl Scouts experience. I saw that girls in our community needed opportunities and became a local Troop leader for Brownies, Juniors, Cadettes and Senior Girl Scouts. I also was an assistant unit leader at our local Trefoil Camp.

I have four children, and in 2005 my third daughter, Amber, was diagnosed with Acute Lymphocytic Leukemia (ALL). I learned to speak up or advocate for her, which also helped me be more vocal in advocacy for my youngest child who had some learning related needs. I became aware that the general population was not aware of resources available and how to use them. Amber and my youngest made me more aware that many needs were just not being met.

Amber had her last treatment for cancer on November 18, 2007. I joined the Primary Children's Hospital PFAC in December 2007. I attended my first meeting virtually, by telephone. I understand I had been referred to the PFAC by a leader of Candlelighters, an organization that supports families with children with cancer.

CAPS: How has your advocacy evolved?

Diann: In the beginning it was becoming aware of resources and a professional side interest in knowing what patients and caregivers needed. I felt like I could bring new insights to the table. I felt I could recognize when a person or a situation needed some kind of advocacy. Over time, I found I could offer ideas and suggestions beyond PFAC meetings. I served on committees that worked on special projects. Then, I had the opportunity to help manage and facilitate the PFAC.

In the past few years I have been helping support my Mother who lives with various issues common to Senior Citizens. Supporting her care made the transition to working with Comagine and issues around Medicare and Seniors a natural shift in my quality and safety focus.

CAPS: What projects have you worked on?

Diann: Loveseats! It may not seem like a big deal to some people, but in waiting rooms all of the seating was single seats. I was part of a design committee that helped advocate for loveseats in waiting rooms. The concept spread from the children's hospital to the entire system. Now persons can sit and snuggle during difficult situations.

Diann (continued): I worked on the design of the Ronald McDonald Room. Even now, finally having a place in the hospital that is a respite area for caregivers makes me so happy.

I helped work on the initial installation of white boards in all rooms at Primary Children's. That also spread to the entire system. Recently I was in an Emergency Room with a family member and the clinicians did not use the whiteboard. We were able to remind them, gently, to fill out the information.

I have an Uncle who was receiving dialysis before he recently passed away. He really benefitted from in-room rounding, another project I was a part of. It makes such a difference when caregivers talk with you and not just about you. I see these projects we worked on years ago moving across healthcare and feel so proud that I played a part in that.

With Comagine, we have been working a lot on written materials to offer guidance to persons on how to access and utilize healthcare.

CAPS: What recommendations do you have for other Patient Advocates?

Diann: Talk to as many people as you can. Ask other people what concerns they may have that could be addressed. If you have a concern, talk to the tech in the room about how the issue may be solved. Then keep asking right up the line of command. Eventually, someone will know how to make a change. Nothing happens if we don't talk to each other.

CAPS: What recommendations do you have for facilities that want to improve Quality and Safety?

Diann: I would encourage persons to be willing to think outside the box. Just because something has always been done one way, doesn't mean it always should be done that way. Please be open to listening to people's questions and concerns and not get stuck on a certain thought pattern.

CAPS: What do you see happening in your future?

Diann: I will go wherever it takes me. There's so much value in advocacy and meeting a patient where the patient is at instead of making decisions based on rules and payment issues. Maybe I will continue to advocate in my own backyard, maybe beyond. I will go where it takes me to make things: Easier, Better, Convenient, and Accessible for those who need the care.

Do you have a question for Diann? You may reach her at dfolkersen@gmail.com. Her website is: <http://diannfolkersen.norwex.biz/>

Speaking of Information . . .

Pandemic Related Resources:

COVID-19 Resources from CDC:

- [People who are at higher risk for severe illness](#)
- [If You Are Sick or Caring for Someone](#)
- [Prevent Getting Sick](#)

Resources curated by the Institute of Healthcare Improvement – a vast treasury of COVID-19 resources may be found [this link](#).

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May 2020



CMS Guidance on Visitation and Discharge for Covid-19 Infection control and prevention:

- Medicare and C-19 landing page: <https://www.medicare.gov/medicare-coronavirus>
- Hospitals, Psychiatric Hospitals and Critical Access Hospitals: <https://www.cms.gov/files/document/gso-20-13-hospitals-cahs-revised.pdf>
- Nursing homes: https://skillednursingnews.com/wp-content/uploads/sites/4/2020/03/QSO-20-14-NH-REVISED-3-13-2020_0.pdf

Project Patient Care guidance on visitor rules in hospitals and nursing homes: <https://www.projectpatientcare.org/wp-content/uploads/2020/04/ppccovid19april5.pdf>

Vizient Covid-19 Resource Page (updated daily): <https://www.vizientinc.com/covid-19>

Patient Safety Movement Foundation (updated frequently): *Helpful Covid-19 Resources* (<https://patientsafetymovement.org/helpful-coronavirus-covid-19-resources/>)

Centers to Advance Palliative Care (CAPC): *COVID-19 Response Resources* (<https://www.capc.org/toolkits/covid-19-response-resources/>)

- CAPC provides a toolkit on communication during end of life/palliative situations customized to Conavid 19 situations

University of Wisconsin: *Best Case/Worst Case: ICU, with Special Content for Patients with COVID-19* (https://www.hipxchange.org/BCWC_COVID-19)

- Designed to help palliative care clinicians and other clinicians navigate daily conversations with patients' families. It also informs critical care clinicians about the lives of the patients they are caring for and supports families who are absent from the patients' bedside.

Advanced Directives and End of Life Care

- Maryland Office of the Attorney General guidance and forms: <https://www.marylandattorneygeneral.gov/Pages/HealthPolicy/eolcare.aspx>
- AARP forms for all States: <https://www.aarp.org/caregiving/financial-legal/free-printable-advance-directives/>
- Respecting Choices: *Covid-19 Resources*: <https://respectingchoices.org/covid-19-resources/>

Project Patient Care podcast, *Advance Care Planning During "Normal" and Covid-19 Times*: <https://www.projectpatientcare.org/podcasts/>

Recommendations for and by Patients, Families, and Caregivers for Elective Surgeries and Invasive Procedures During COVID-19 Pandemic:

<https://www.projectpatientcare.org/wpcontent/uploads/2020/05/patientandcaregiverperspectiveselectivefinal.pdf>

Patient Safety Movement Foundation:

- *Guide to Medical Care at a Distance*: <https://www.dropbox.com/s/m052xhjxsjsrjv/Guide%20to%20Medical%20Care%20at%20a%20Distance.pdf?dl=0>
 - This infographic outlines what patients, families, and advocates can do to engage from a distanced during hospitalization. Organized by four stages:

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May 2020

- Continued: Organized by four stages:

1. Admission
2. Daily, during hospitalization
3. Discharge
4. After discharge

- *Hospital Plan of Care* (Form designed for family caregivers to use to get the necessary information from the care team):

<https://www.dropbox.com/s/ro06j84zpmssqgnw/POC%20Blank%20April%202019.pdf?dl=0>

Centers for Disease Control and Protection (CDC): *Coronavirus Disease 19 Daily Life and Coping*
(<https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/index.html>)

National Alliance on Mental Illness (NAMI): *COVID 19 Information and Resources*
(<https://www.nami.org/Support-Education/NAMI-HelpLine/COVID-19-Information-and-Resources>)

American Association for Retired Persons (AARP)

- *6 Questions to Ask if Your Loved One Is in a Quarantined Facility*
(<https://www.aarp.org/caregiving/health/info-2020/questions-for-quarantined-facility.html>)
- *The COVID 19 Imperative: Keep Family Caregivers and Long-Term Care Facility Residents Connected*
(<https://blog.aarp.org/thinking-policy/the-covid-19-imperative-keep-family-caregivers-and-long-term-facility-residents-connected>)

Morale & Gratitude:

- Blog post: *In a pandemic, does patient feedback still matter?*
https://blogs.bmj.com/bmj/2020/03/30/james-munro-in-a-pandemic-does-patient-feedback-still-matter/?utm_source=twitter&utm_medium=social&utm_term=hootsuite&utm_content=sme&utm_campaign=usage
- Twitter thread: *7 tips on boosting the effects of gratitude:*
<https://twitter.com/GiskinDay/status/1241303041015513088>
- AARP: *Innovative ways to say thank you.* <https://www.aarp.org/health/conditions-treatments/info-2020/tributes-to-health-care-workers.html>

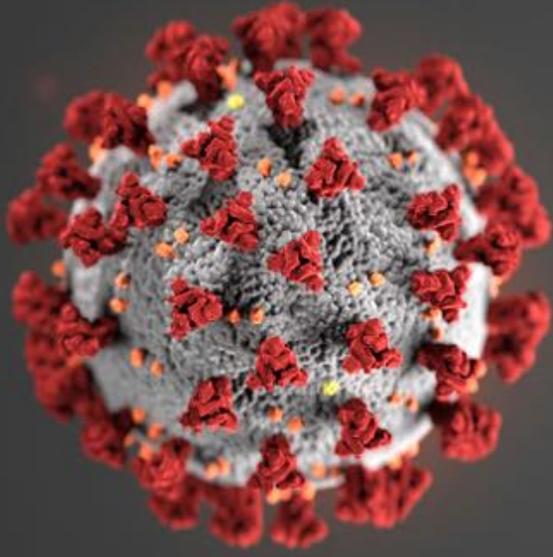
Thanks to CAPS Board Member, Marty Hatlie, JD, for compiling these resources.

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May 2020



Coming to the CAPS YouTube Channel [\(here\)](#):



COVID-19



Patients, Families and Providers

Three Voices, One Conversation

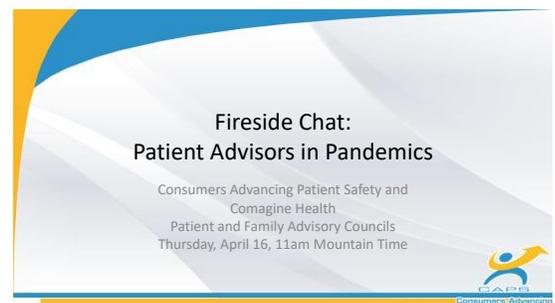
Please check out this *archived* event [At this YouTube link.](#)

A Fireside Chat: Patient Advisors in Pandemics

Patient advocates from the Consumers Advancing Patient Safety Consumer Advisory Panel and the Comagine Health Patient and Family Advisory Council met together to share robust discussion about Patients in a Pandemic. They explored issues with great relevance to patients, caregivers and providers. Comagine's Kimberly Mueller, LCSW, and Joan Gallegos, MSW, RN shared coping strategies and talked about stress relievers for persons who may be at home or persons whose loved ones were in hospitals or congregant living situations.

Advisor Jodi Hansen expressed the importance of hope. This topic evoked many responses and persons noted the importance of compassionate communication, especially in times of unique stress. Advisor Diann Folkersen addressed how even providing simple choices boosts patients' sense of autonomy. Advisor Rachel Weissburg noted the importance of Advance Directives and having these discussions now with all adult members of a family unit. Advisor Chrissy Blackburn noted that patients have contributed to tools that will be available at her facility to guide patients in advance planning. Advisor Janice Tufte touched on the importance of understanding equity issues and the social determinants of health. Advisor Maurice Wells, for example, shared how meals were available for senior citizens in his community.

You will find this recording contains great insights and resources as you look at how Patients approach a Pandemic.



Fireside Chat:
Patient Advisors in Pandemics

Consumers Advancing Patient Safety and
Comagine Health
Patient and Family Advisory Councils
Thursday, April 16, 11am Mountain Time



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

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Send it to capspatientsafety@gmail.com

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