# Physics Girl Livestream Notes and Q&A - 7/6/2024

**Editor notes:** These notes and questions and answers are not a word for word transcript. I have ME/CFS, though milder than Dianna, and while I have experience taking notes quickly, I do not have the capability to transcribe word for word.

**Livestream link: Physics Girl LIVE with long Covid**

## Livestream Setup

From twitter: “We are live-streaming a full day of Dianna’s life, sharing what it’s like for someone suffering from severe MECFS.

We will also be raising money for the Open Medicine Foundation to support research and clinical trials for ME/CFS and Long COVID.”

Donations are still being accepted through YouTube at the link above or directly with the Open Medicine Foundation.

For the Physics Girl’s live stream they are showing Dianna in one screen in bed and presenting in a second stream. The room is dimmer than it looks. The exposure is turned up on the camera for viewer visibility.

It was Dianna's idea to do the livestream. She had wanted to do it last fall but she hasn't been well enough to do it due to her health.

Simone Giertz is one of Dianna’s dearest friends and helped present with Kyle Kitzmiller, Dianna’s husband.

Kyle and Dianna have decided not to share specific information on her medications and supplements. Different patients respond to different treatments and all treatments should be discussed with an individual’s medical team.

The original fundraising goal was for $10,000 and that was achieved in the first half an hour.

Before and during the livestream they took questions from supporters.

Levi, Dianna’s editor and videographer, was instrumental in helping with the event. He also is extremely supportive in her and Kyle’s life.

## ME/CFS Basic Information

There is no widely used diagnostic test for ME and there is no cure or even standardized treatment. A lot of specialists for ME are slammed with patients. There are tests that show physiological abnormalities in people with ME but there is no standardized diagnostic test yet.

**Resources**
The Sick Times is a good COVID resource. Health Rising is a good resource for scientific and research information on ME/CFS and Long COVID.

**Dianna's Condition**
Dianna can't speak very much. It takes a lot of energy so she writes on an electronic tablet to convey messages. Dianna is presently completely bed bound and Kyle is her caregiver.

Dianna does worse on days directly before and during her menstruation. Her symptoms were worse than usually for the livestream because she had just started her period.

**Onset of Long COVID and ME/CFS**
Before COVID, Dianna got sick longer than her peers. She also had some digestive issues. She even had brain fog when she ate certain things.

Dianna caught COVID not long after her and Kyle got married even though they were trying to be careful. Kyle and her had been training for a 100 mile hike for their honeymoon. They tried to do the hike and she completed two days and then the third day she crashed hard.

She started having anxiety issues spontaneous with the onset of Long COVID.

Dianna was still trying to do walks. 20 minute walks.. 10 minute walks.. Then eventually she became home bound and then bed bound. They didn't realize that exercising was harmful to her and people were advising her to exercise.

**Comorbidities**
Dianna's MCAS, Mast Cell Activation Syndrome, is so bad that if someone is visiting her they have to use a special soap and shampoo on themselves, as well as wear clothing washed in a certain soap. She has SIBO, Small intestinal bacterial overgrowth.

**Diet and Meds**
Dianna has MCAS as well and is sensitive to even fillers in her meds. Kyle, her husband explained that she has her meds compounded into coconut oil. Every morning he makes her some "pancakes" out of nuts (ground pistachio and pecan), apples, vanilla, carrots, and chia seeds. Her diet is fairly limited. She can't tolerate a lot of different foods. She also can have butternut squash and coconut milk. Dianna drinks her water with salt in it to help maintain blood fluid volume. (It is a common practice for Orthostatic Intolerance like POTS). Kyle carefully tracks her food intake. Apparently she eats more now but at one time she could barely eat anything so they had to track closely that she was getting enough nutrients.

**Dianna's crashes**
All symptoms get worse, headache increases, flushing, reaction to food increase, stomach cramps, nausea, energy level completely tanks, can tolerate sensory stimulation much less. It can take days, weeks, even months to improve.

Washing Dianna's hair even in bed and using a special shampoo can cause her to have a crash.

**Trying New Medications and Foods**
It can be difficult to try new medicine and new foods, because they have to be careful to only change one factor to properly evaluate results.

**COVID and Long COVID and Masks**
Masks do work to protect health.  For each time someone catches COVID, the higher the risk that someone will develop Long COVID.

**What causes Long COVID? Answers by Kyle**
During a Long COVID study, researchers pulled IgG antibodies from patients with LC and injected into mice and they developed symptoms. They also used IgG from patients with subsets of symptoms and injected mice which ended up mirroring the symptoms of patients.

Reservoir of viruses might be driving Long COVID / ME/CFS. Viral RNA has been found in the gut of Long COVID patients.

**Editor's Note:**  Study - **Transfer of IgG from Long COVID patients induces symptomology in mice**

**Nasal Vaccines**
Nasal vaccines are being studied to see if they work better than regular vaccines.

**Brains of Long COVID patients**
Physical changes in the brain of Long COVID patients can be seen via MRI.

"If you're not scared of Long COVID, you should be."

**What do you wish you had done differently when Dianna got sick?**
If you get COVID you need to rest well afterward. Don't try to push through symptoms or take on too much too soon. Everyone is taught that exercise is good for you, but it is very important to rest.

**How does Dianna go to the bathroom?** She uses a bedside urinal with assistance.

**How does Dianna wash herself?** Kyle uses rinsed baby wipes to clean her.

**What is her laundry protocol?** Kyle used to boil sheets at home. Couldn't use public washers because it transfers smells/soap. Now they have access to a washer that soap hasn't been used in.

**What is something that gives Dianna joy?** Holding her hand. Getting questions answered. When she is better,  she can listen to some music or read about celebrity gossip. Using a paint

by numbers app.

**What does Dianna  miss the most?** She has a hard time putting herself in a position of wanting, because there is no end in sight. Right now she has to take each day at a time. If she was better today, she would want to spend time with friends and go for a hike.

**Stockdale paradox.**  It helps Kyle. Hold two things in your mind at the same time. You have no control and you have to be realistic about how bad your condition is and also have hope and belief that one day you are going to get better without setting a time frame.

Editor Note: Admiral Stockdale who survived a prisoner of war camp, "This is a very important lesson. You must never confuse faith that you will prevail in the end—which you can never afford to lose—with the discipline to confront the most brutal facts of your current reality, whatever they might be."

**Dianna's Routines** Four meals and a snack. They break up washing on different days for tolerance. Some days red light therapy. Dianna has a checklist. She tracks her screen time. Texts minimally with friends. Sometimes it is easier to talk to less close friends.

**Kyle, How are you looking after yourself?** He tries to stay very active - going for a bike ride, lifts weights, rock climbing, plays games with friends. He finds having planned events very helpful.

**Onion support** - Simone mentioned that people should support the people that are further in layers and seek support from those in outward layers.

Simone comment: When she was sick with a brain tumor and recovering, the least helpful comments were "Reach out if you ever need to talk." Most helpful - practical assistance.

**Kyle caregiving thought** - Being a caregiver is very difficult, especially seeing someone you love suffering. As a full time caregiver, he finds life coaching sessions once a week helpful. Dedicating time to personal growth and development has been beneficial.

**Has being a caregiver made you a better person?** Kyle would have really preferred to never have gone through this. He picked up resilience. Picked up the skill as being a caregiver and skills to face adversity. He doesn't let his role be something that only drags him down.

**As someone who also has an amazing caregiver, what can we do as a patient to make it easier for you?** It heartens him when Dianna shares with him when she is making a plan and participating in her future both small and big. It gives him direction on what he could do to assist her. He enjoys compliments.

**Second presenter Ian**
Ian Hecox met Dianna in 2019 at the YouTube Creator's Summit. He had one of the OG creator channels with Smosh. He used to spend time outdoors with Dianna  by being active -

hikes etc. He also has to change how he talks to her because he tends to follow tangent after tangent normally.

**Discussion between Ian and Kyle:** Long COVID and ME/CFS are such a lonely disease. Dianna and Kyle thought it was important to show how someone with severe ME/CFS is affected.

We equate morality and worth with productivity. LC and ME/CFS takes away the ability to be productive. There is a lot of complicated psychology with the disease.

Historically ME/CFS has only received 7% of the funding in relation to its disease burden on society.

OMF has received $10,000 in donations directly today. The YouTube stream has directly raised $93.5 thousand so far.

So many medications for LC and ME/CFS are off label and some patients have to pay for them directly because insurance won't cover the treatments. Formal clinical trials can change that.

Some physicians require patients to see them in person which can be a huge burden for a severe ME/CFS patient. Common tests come back normal, so patients aren't getting diagnosed and treated.

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It is estimated that of the 85 million with ME/CFS, 25% are bed or housebound at some time during their illness.

**What is Dianna's favorite thing to talk about when she does?** She makes up silly songs and parody songs. She finds celebrity and content creator gossip digestible in her condition.

**Is she able to read a book or listen to an audio book?** No, it is too difficult. She has to be very careful with stimulus. She can enjoy small clips, but still might have to recover.

**How is Dianna's sleep and dreams?** She sleeps about 11 hours a day and takes small naps throughout the day. She spends about half her time sleeping. She has super vivid dreams.

**Does she have to worry about bedsores?** She moves enough that is not an issue. Kyle is able to help her clean her body a bit each day.

**Has Dianna tried brain retraining?** There is a small percentage of people where it can be very helpful, but for the vast majority of people it doesn't address the root cause of symptoms. It is a misconception that it is/can be a cure. Dianna has had no success with it.

**Can you explain why/how chemicals can cause a reaction?** MCAS - Mast Cell Activation Syndrome. Mast cells are all over the body and involved in immune and inflammatory response. In MCAS, this happens all the time when it shouldn't and is unpredictable. This

causes allergy symptoms, sometimes severe ones. It has been a large road block in Dianna's recovery, especially since it can trigger PEM and set her back.

**What does Dianna use her smart watch for?** Communication and monitor vitals - heart rate, heart rate variability.

**Will you post each interview eventually?** The live stream will be available. Dianna will need to make decisions on posting them to the channel.

**People were asking about tick borne disease, EBV, and other potential underlying conditions.** There is a lot of uncertainty with LC and ME/CFS. The science isn't there to give concrete answers. Dianna is so sensitive to medications. They are unsure if long courses of antibiotics would work.

**What does Dianna think about things while she is laying there?** Most times she is too sick to think about things. A lot of times she lets her mind wander.

**How long is a crash for Dianna ?** A crash is a prolonged period of time where her system gets worse and they can last weeks, sometimes months. Heart rate gets higher. Her chest tightens. Brain fog (cognition) gets worse causing confusion. Increased nausea.

**Continued Discussion** Kyle hadn't seen a YouTube video until he met Dianna. He doesn't recognize content creators at events.

Kyle corrected Ian not to just use "Chronic fatigue" but ME/CFS.

General wisdom like exercise, getting sunshine is contraindicated for severe ME/CFS patients.

**What is the difference between PEM and a crash?** Kyle says that to him PEM is more short term and a crash is longer.

Editor's note: PEM and crashes are generally considered the same with ME/CFS medical experts.

**Masking** - The more time you are infected with COVID the greater the chance for getting Long COVID. Two way masking is important to reducing the chance of infection of COVID and therefore reduces the chance of Long COVID. Study - Plane flights and who got sick. Unmasked - there was a 25x higher risk of infection than short flights. For flights with two way masking they didn't register any cases of COVID transmission. Masking is effective. We need to continue to discuss this as a society. For game nights with Kyle at the apartment, friends come over masked. A lot of people can't afford to get COVID and especially Long COVID especially as severe as Dianna has.

Editor's Addition: **Study shows enforced masking on long flights prevents SARS-CoV-2 transmission**

**Study -** Took antibodies from LC patients and gave them to mice and the mice exhibited LC symptoms. They split the LC patients into symptom sub-groups. The mice injected with the subgroup blood exhibited the specific symptoms that the LC patients had. (See link far above)

**What is Kyle's favorite board game?** Carcassonne. Played with Dianna for the first 6 years of the relationship and never won a game. Then he started playing really dirty and he started winning sometimes.

**Can she sit up in bed?** Dianna can, but she doesn't do it often because it can trigger PEM (Post Exertional Malaise). Sometimes she will prop herself up. She wanted to start trying to sit up every day, but then she had a bad reaction to a medication and it set her back. It is out of reach right now.

**Studies and Stats -** LC might be from viral persistence in the tissues of the body. Persistent viral MRNA. Women are almost twice as likely to develop Long COVID.

**Has Dianna tried doing physical therapy?** Dianna tried leg movements, but she got a lot worse. Two sessions of physical therapy in the 2 years she has been bed bound. One at the six month mark another at the year mark. They both lasted a couple of weeks and ended with Dianna being crashed for a few months. The most intense movements were something like the leg drag. During physical therapy there was no increase in strength or performance. One theory is that patients with PEM, damage their muscle fibers and all the waste products build up and there is no repair cycle like "normal".

**What steps do you take to combat deconditioning / muscle degradation?** She is between a rock and a hard place. Underlying pathology needs to be fixed first before she can directly combat deconditioning.

**Is there a correlation between ME/CFS and traumatic brain injury (TBI)?** Initially Putrino's clinic treated LC patients like TBI patients because the symptoms were similar. But unfortunately the physiology does not match. TBI rehabilitation was making patients with PEM worse.

**My wife suffers from clinical depression and while the symptoms are different, ME/CFS and depression patients both get stigmatized and misunderstood. How do you deal with this and what can people do to educate others?** In the past, the pressure has been on patients to do interventions. Kyle wants to see a shift in medicine for these conditions for the burden to be placed back on the clinician not the patient. We should be doing what we can to support patients without placing undue burden on them.
Ian: We are better off listening to patients than giving uninformed advice.

**Do you have to avoid making her smile?** Sometimes, yes. We have to limit her energy output collaboratively. Sometimes it just isn't the right time.

**Has she tried a weighted blanket?** She did but it made it harder for her to breathe and she expended more energy.

**When did you first learn about ME/CFS?** Dianna brought it up about four months after the onset of Long COVID. It took about 10 months to get a diagnosis. There aren't enough doctors to treat the number of patients.

**I've been dealing with MCAS since COVID. It has been a long journey and local doctors don't know anything about it.** Get on a waiting list for a doctor who treats patients virtually. Local doctors are great when they know about it, but in some conditions there isn't enough recognition. MCAS is pretty new in the medical field.

**What effect did hyperbaric oxygen treatment have?** They did 10+ sessions, but it didn't seem to have a marked positive effect. There hasn't been a lot of good evidence. What we are seeing is that a lot of patients have good blood oxygen levels but it isn't getting into the tissues.

**What can we do to help make care for Long COVID accessible? Do we harass the insurance companies like we do politicians?** Kyle wishes he knew. He knows that insurance companies are going to play a role in this. There is an intersection of politics and healthcare. The way you vote makes a difference. Contacting politicians will make a difference.

**Mold?** We tested the whole house for mold. We had some at the house before. In tests she has been markedly clear.

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**Apples** - Envy apples are delicious and they originally came from New Zealand. Sugar bee apple blew Kyle's mind. Cosmic crisps.

**How are you doing as a caregiver?** Kyle had a long period of being more depressed and had so much chaos and loss. It has taken him a year to get my life on track. Patreon donations have been amazing, so he didn't have financial stress on top of being a caregiver. He was able to eventually start doing projects of his own, exercising, and hanging out with friends. He was really sad and depressed for a while. His future with Dianna seemed to be slipping away. The support from you guys made a difference.

**My doctor doesn't do anything but refer me out from specialist to specialist. How do you find a doctor that knows about Long COVID?** Most specialists that treat complex diseases like ME/CFS are not in the insurance system. (They aren't because they can't stay open with insurance contributions.) They need to spend unusually long with patients and insurance doesn't reimburse them for their time and efforts. Try to find centers that treat complex illness. Many have very long waiting lists. It is difficult to get care.

**What FDA approved medications was Dianna treated with before alternative therapies and medicines were used?** There are no FDA approved medications for Long COVID or ME/CFS. This is the world we are living in and that is part of the reason they are doing this fundraiser. We need research to prove that medications work and they can go on a list of

approved medications and insurance will cover them.

**Advice:** Gather the resources from the Bateman Horne Center and give them to your doctor. It isn't fair for the burden to be on patients, but it is how things are right now.

**Unrest:** Kyle couldn't watch it, because it was too emotional.

Editor addition: Good documentary with a more science focus is “Living with Chronic Fatigue Syndrome” (2021) https://www.youtube.com/watch?v=YH1wn3D9HNg

**Can you get diagnosed with Long COVID without ever being tested positive for COVID?** Kyle is not a doctor. He imagines that it would be challenging. You could be diagnosed for post viral illness like ME/CFS, orthostatic intolerance (ex: POTS), MCAS, etc. It is complicated. It would be a challenge. Dianna took 6 rapid tests on their honeymoon.

Audience Comment: They were diagnosed with long haul without a positive test. It took months to narrow down that it wasn't other conditions.

**Does Dianna ever have a good day? What does it look like?** The trend is slower. Building up to a few good days. She is talking more and joking more and feeling more vibrant. Then she will start to go down with more symptoms and depression.

**How does she feel in comparison to a year ago? Is the trend upwards?** It is pretty level to be honest. There were worse times last year but she hasn't regained any significant functionality. Her negative symptoms are less, but she can't do more without getting PEM. Maybe slightly up? She hasn't had to go to the hospital recently and she is more stable. Her progress is slow and unpredictable.

**Is there any idea for a time scale for long term recovery?** Kyle doesn’t  think we understand it well enough. Some patients between the 6 month and 2 year mark report seeing recovery to 80% and a lot of people still have symptoms 3-4 years on. There is something underlying that is persistent with people with Long COVID. Some make a full recovery but the time scales are all over the place.

Audience comment: ME/CFS has only a 5% full recovery rate. Many patients have been sick for decades.

**What is the research on this outside of the United States?** One of the reasons they selected the Open Medicine Foundation is because it is an international effort.

**Are you going to do another fundraiser?** Kyle and Dianna have other researchers and organizations in mind. Some have reached out and would love to do an interview. He won't be focused on it for a while, because they both need to recover.

**Is she currently sick with COVID or do her symptoms have nothing to do with COVID but allowed her symptoms to pop up?** There is a theory that people with Long COVID have COVID reservoirs in the body. Some viral MRNA is found in patients years after getting infected. Dormant infections like EBV sometimes pop up on tests. Coinfections reemerge.

**How do you stimulate Dianna's mind?** We are pretty good at chatting and make each other laugh. She craves human interaction.  goes to bed at around 7 PM.

**Outcome:**
There were between 2500 and 4,000 people for the entire stream. Total an hour after stream end - $109,553.00. OMF indicated earlier that they had collected $10,000.