

Statement Regarding the Cystinosis Community and Covid Vaccines
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As the epidemic progresses and we now have the option of Covid vaccines, the question of if or when to take them and vaccine hesitancy has become important. I was asked to contribute a personal message for the cystinosis community.

Let me start off by clearly delineating my position.

1) I am firmly committed to vaccines and believe they are a tremendous good for ourselves, our families and our society. Most of my professional colleagues likewise support vaccines.

2) I received the 1st dose of the Pfizer vaccine on December 19. I have attached a picture of me actually getting the vaccine. My wife is booked to get her first dose on Thursday and my children when their turn comes up.

3) I run the largest pediatric kidney transplant program in the country. Vaccines are a vital and integral part of our program to manage the health and well-being of our patients. Vaccines protect not just the patient but the other ill patients they come in contact with on the organ transplant ward and in the clinic. There are clearly documented episodes where an unvaccinated organ transplant patient has spread influenza to multiple patients on an organ transplant ward and clinic. Vaccines are so important that unless they are medically contraindicated we mandate them prior to accepting a patient for a kidney transplant.



Okay, now that's done.

Patients who have cystinosis are immunosuppressed by their malnutrition and their chronic kidney disease (CKD). Therefore they are at higher risk than others for many diseases. There is clear data that taking influenza vaccine substantially reduces the risk of death and hospitalization in patients living with organ transplants or kidney failure. There is also clear data that otherwise perfectly normal people die of influenza very commonly in the United States. I have seen this tragedy many times where a previously perfectly healthy, normal student spends days to weeks in the ICU and dies from plain old influenza. Imagine the torment of the parents wondering why they didn't make the effort to get the child vaccinated. Covid is worse. It is killing many, many more people than influenza. It is also much worse for those who have kidney disease. The centers for Medicare and Medicaid services show that **half** of all the Medicare beneficiaries who have been hospitalized for Covid carried the diagnosis of chronic kidney disease or end-stage renal disease. Hospitalized Covid patients with CKD are have more than double the death rate compared to patients who have normal kidneys. This means any cystinosis patient on dialysis or with CKD is at much higher risk for hospitalization and death from Covid. For this reason kidney specialists are putting pressure on the government to prioritize Covid vaccinations for CKD patients. This may not be an issue for children who still have pretty normal kidney function but we don't know.

If you have had a kidney transplant you are at least partially protected from severe Covid disease. I have cared for more than 15 children who have developed Covid infection after a kidney transplant and only 2 of them even needed to come into the hospital and then only for a single day of diarrhea for one, and 2 days of a fever for another. It seems that the medications used to protect you from rejection reduce the severity of the immune response to Covid and it allows your body time to heal without becoming full of

inflammation which is the cause of death in older patients. It is not a guarantee, but it is reassuring. The danger is that these people are likely to become asymptomatic spreaders. Feeling no symptoms but endangering other people by spreading large amounts of the virus because of their weakened immune systems.

The Center for Disease Control (CDC) issued guidance on December 28, 2020 that the messenger RNA Covid vaccines (Pfizer and Moderna) may be administered to people with underlying medical conditions which include immunosuppression and autoimmunity as long as they do not have a history of very strong/severe allergic reactions. They stated that although there is no definitive long-term evidence that they are completely safe in that population, the short-term evidence is that they are safe in immunocompromised patients.

Let's talk about some of the objections people have to vaccines.

1) Vaccines are full of toxic chemicals and you can die from a vaccine or become severely injured.

Well, there are a small number of people who can be injured by certain vaccines like the influenza vaccine. Some vaccines include an adjuvant which is a chemical substance that irritates the immune system to make it angry and ready to make a response to the killed virus or pieces of virus in the vaccine. There are some people who can have a side effect of the adjuvant such as an autoimmune reaction, but they are super rare and do respond to treatment. Refusing to take the vaccine because you are afraid of a rare side effect is like not going to the emergency room if you believe you are having a heart attack because you are afraid of being hit by a car in the parking lot. Nothing is without risk. We weigh the benefits and risks of our actions every day we step out the door of our house. For vaccines, the chance of benefit is very high and a chance of harm is very low so why would you risk those odds? The data shows time and time again that healthy people unnecessarily die of vaccine preventable diseases. These same diseases that are preventable with vaccines put people with chronic illness at much higher risk of dying. The data also shows the rate of complications from vaccines is very low. To further assure people who are hesitant to be vaccinated, there are programs with federal funding that exist to compensate people for the very rare cases of vaccine related injury. By the way, the current Covid vaccines have no adjuvant, no Mercury, no heavy metal.

2) Vaccines are not "natural" and it's better to get the natural disease.

This argument fails to consider that contracting the natural disease is far from benign. It can result in severe outcomes including death. Nature is not a nurturing, kind nor motherly entity. Nature has no care for the individual, or about anybody's pain or suffering. In the words of Alfred Tennyson, "Nature, red in tooth and claw"; Nature only cares about strengthening the species. Nature doesn't care about suffering, nature makes parasites that cripple and slowly kill, Nature is a pride of lions descending on a deer and ripping out the belly while the deer is still alive. Nature does not want the weak to survive. Protecting and loving our loved ones with cystinosis goes against nature. We want them to survive and thrive but, because nature believes in culling the ill, nature sets infections and parasites and other suffering against people with chronic disease. For the medical community and the loving families of patients with chronic disease such a cystinosis, we do not want nature to take its course. We want people unlucky enough to be born with a hereditary condition to live as long and as healthily as possible. This means we have to embrace therapies that may appear unnatural, such as dialysis, organ transplantation, vaccines and, hopefully one day, stem cell transplantation.

The Covid vaccines safely cause a natural response and resistance to the virus. The Moderna and Pfizer vaccines are mRNA vaccines, which means when they are injected into the muscle of your arm, the mRNA get into the cells of the muscle and tell the cells to make one protein of the 29 that make up a Covid virus- the spike protein. When your arm muscle makes the spike protein your body identifies it as foreign and starts an immune response. That is why your arm is sore the next day and you may get a bit of what feels like a cold or flu which is the manifestations of your immune response revving up. Those sensations are not an infection, but the feeling your body has when the immune system is going to war. But it's nothing like getting the actual virus because in a day or two the symptoms go away and you don't end up sick and in the ICU.

The science behind the Covid vaccine has taken some tricks from nature's playbook. With other vaccines like the flu vaccine or the vaccine for measles, for example, you get bits and pieces of the virus that have been grown in chicken eggs or a test tube. The virus is either dead in the case of the flu or weakened in the case of measles but when you get these vaccines, there are not one but a whole bunch of proteins which trigger an immune response. And, because those proteins have been grown in the lab, processed, purified, shipped, and stored they can become damaged and cause some side effects. But the mRNA vaccines avoid **all** of this. They do exactly what the virus would do... Inject mRNA into the arm muscle cells and enslave the cell machinery to make a protein which triggers the immune response, but in a pure form and in the body where it needs to be. No shipping, no storage, no processing... It is important to understand that when the Covid **virus** enslaves the cell machinery the cell makes the 29 different proteins that are needed to make millions of actual infectious viruses, in comparison to the mRNA vaccine, which makes only one protein.

I like the following analogy. Just imagine the Covid virus is a car, it has tires, wheels, an engine, chassis, and body, windows, steering wheel... You get the idea. When you get infected with Covid, you make billions of little cars. The vaccine is the blueprint for making tires... Just tires. So when you're vaccinated and your muscle cells start making a whole bunch of Covid tires, your immune system gets educated about these foreign tires and gets ready to fight them. Now, when the actual Covid virus comes along and a few of your cells get infected with the **whole** Covid virus, your immune system says "I don't know what that thing is, but I sure recognize those tires... **ATTACK THEM!**" And when your immune system destroys the tires, the cars can't spread in your body. You win and the virus loses. This is why I think the mRNA virus is so safe. It does basically the same thing that the actual virus would do but in a safe way that protects you.

3) These vaccines are made with cells from aborted babies.

This is just false. The Pope of the Roman Catholic Church has come out with a statement that good Catholic Christians should take the vaccine when it is available because it is protecting people who are alive today and are at risk such as the elderly and the infirm. In the Hebrew faith that would be called at mitzvah. A good deed done from religious duty.

4) You might be reading on social media horrible stories of people having severe allergies to the vaccine.

And, if you are in certain social media circles you might be hearing about people dying from the vaccine. The reality is that there is as yet no known case where a person has died from the Covid

vaccine. It is true that there are some people who can get severe (but treatable) allergic reactions just like you can get a severe allergic reaction to eggs or peanut butter. Does that mean you should ban the poultry and peanut butter industry because of extremely rare allergic reactions? No. The vast majority of people benefit from eating eggs and peanut butter as a source of protein so we take precautions and carry on with our lives.

5) **Maybe you don't like to be told what to do.**

Fair enough. But just like seatbelts, in the 1960s, some people didn't like being told to wear seatbelts. But now it is the norm and the vast majority of people see the benefits of seatbelts. Is it fair to make others pay for your costly ICU stay through higher taxes or increased health insurance premiums if you get sick from Covid because you have decided not to take the vaccine? If you choose to not take the vaccine and you then infect an elderly person or ill person who then dies – how would you feel? In our society we started out with an emphasis on both the rights **and** the obligations of being a citizen. In the last little while you rarely hear about your obligations as a citizen but taking the vaccine to protect the weaker and less fortunate is a prime example of such an obligation.

6) **You may believe that this is a giant conspiracy by Bill Gates to control your every thought and deed using nanotechnology and the 5G network.**

I got nothing. You figured it out. The New World order is not as smart as your Facebook social media. Say hi to Q for me!

But seriously, when it comes to vaccines you need to be careful that you are not being misled by mistruths. Well intentioned people can inadvertently spread false information. And there are people who knowingly peddle these lies for reasons that I cannot begin to understand. Many of the anti-vax beliefs contradict each other and do not stand the test of logic or stand up to fact checking.

So, in summary, I recommend you and your loved ones get the vaccine as soon as it is available to you.

Paul Grimm

Heartfelt thanks to my high school friends who edited the earlier drafts.