

Testimony of Rabbi Stacy Rigler  
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Dear Senator Cappelletti,

I want to share a little about my daughter. Maya is a two-time cancer survivor. At two years old she was diagnosed with a Wilm's tumor and treated successfully at Children's Hospital of Philadelphia. At 10.5 years old she was diagnosed with a second, unrelated cancer. The first cancer left her with one kidney. The second cancer treatment damaged her remaining kidney, required removal of her spleen, decreasing her immune system, and removal of part of her pancreas, leaving her with a pre-diabetes diagnosis. She is currently 5 years off treatment and doing well. This Summer she had an onset of strange symptoms of fatigue and spent several nerve-wracking weeks in the hospital. She was then diagnosed with an auto-immune disease and put on immunosuppressants. These aren't all her medical issues, but many. Needless to say, our concerns about her contracting covid are significant. We are blessed to be able to restrict our activities and keep her safe.

We signed up on the Delaware county COVID vaccine form, indicating our care for a child with underlying health conditions. Then we found out that individuals ages 16-65 would qualify to be in group 1A.. We were overjoyed! This is when the challenges set in. While I waiting for Delaware county to update their website, within two days I learned that they had no Pfizer vaccines and would not be vaccinating individuals ages 16-18. As you may be aware individuals under 18 can only take the Pfizer vaccine, the Moderna vaccine is authorized for use in 18-year-olds. I reached out to my daughter's primary care doctor, her oncologist, endocrinologist and, nephrologist - none had information on the vaccine. I looked on the PA state website but was unable to understand which health care systems had the Pfizer vaccine.

A friend told me they had vaccines at a health care center in Lancaster. I tried to create a portal (and tried to call several days in a row). It seems you can not create a health portal if you are under 18. You can create one as an adult, then call to have a child added, but those children were not eligible for the vaccine because they had not been seen by a provider. I wrote several lawmakers. My county commissioner told me of two sites in our county that had the vaccine, so we signed up on their sites. If they do or do not have the right vaccine remains to be seen.

I have two master's degrees, have navigated the challenges of childhood cancer twice, and have discretionary time and wifi service to navigate these things, and still, I am at a loss as to how my daughter might get a vaccine. CHOP now has information on its website, though I have no understanding as to how that process will work or how likely she is to get a vaccine from CHOP.

To be honest, I wasn't even thinking about her getting a vaccine in January. I want to ensure all our essential workers and those with more dire health conditions are vaccinated first. And, when the decision was made to include her and so many others in 1a.. that set off a feeling that if I could try harder then I could get her a vaccine. So off I went, the desire to keep her safe led to frustration and anxiety.

I hope that the state can evaluate our current system, set some reasonable guidelines for how individuals can get vaccines, streamline the registration sites and distribution, and make the information more digestible and easy to navigate. The confusion and misinformation just lead to more anxiety and frustration. Even today I got an email from the county, buried in the paragraphs is the sentence, we will not be able to vaccinate 16-17-year-olds. Thank you for any help you can give, especially to families of sick 16-17-year-olds about how we can access the vaccines and keep our children safe.

Sincerely,

Rabbi Stacy Rigler