

## Q&A: Discussion on COVID-19

### ***Coping with COVID-19: An Informative Conversation for Families in the Childhood Cancer Community***

Thursday, August 27, 2020 - 1:30PM EST

#### ***Discussion Leaders:***

Jeffery J. Auletta, MD - *Director of the Blood and Marrow Transplant (BMT) Program  
and the Host Defense of Immunocompromised Infectious Diseases Program*

Rhonda Ryan, LMSW - *Director, Family Support Program at **Friends of Karen***

Kim Buff - *Founder and Executive Director of **Momcology***

*Hosted by:*

Solving Kids' Cancer, Friends of Karen, Momcology, The Max Cure Foundation

### **GENERAL INFORMATION**

- The Centers for Disease Control and Prevention (CDC) website addresses many common questions people may have about COVID-19:  
<https://www.cdc.gov/coronavirus/2019-ncov/faq.html>
- The World Health Organization (WHO) website holds useful information, as well:  
<https://www.who.int/emergencies/diseases/novel-coronavirus-2019>
- Information and responses below are subject to change based upon a rapidly evolving pandemic. Please consult with your child's primary medical team for any and all medical advice and your child's hospital for its up-to-date hospital policies regarding COVID-19.
- Please understand that not all respiratory symptoms are due to SARS-CoV-2, the virus that causes COVID-19. Currently at Nationwide Children's Hospital, rhinovirus (common cold virus) and metapneumovirus are very common. However, if your child exhibits fever, cough or shortness of breath (current screening symptoms for COVID-19), then he or she will likely be tested for SARS-CoV-2.

## RISKS

- 1. My child is out-off treatment but has an autoimmune disease. (ulcerative colitis). Will this complicate his response if he gets COVID? Adults with diabetes etc. get hit hard?**

Children with compromised immune systems are at higher risk for severe COVID-19 as defined by hospitalization or requiring intensive care. However, most immunocompromised children have either not had COVID-19 or had mild-moderate infection despite receiving immunosuppression. Risk for infection is affected by underlying autoimmune disease severity and control as well as intensity of immunosuppression that the child receives. So immunocompromised children who have well-controlled autoimmune disease have lower risk for severe COVID-19.
- 2. Three years post-stem cell transplant, would my daughter still be considered immunocompromised?**

Congratulations! As long as your daughter does not have graft-versus-host disease, is not taking any immunosuppressant medications like tacrolimus or cyclosporine, and has received her post-transplant immunizations, then she is probably no longer immunocompromised. However, your daughter's primary transplant team knows her the best and can answer the question most effectively.
- 3. Our daughter ended up with disseminated varicella and on a ventilator 9 days during her second year of treatment for ALL (5 years ago. She is now 10). Does this experience place her at a higher risk of getting pneumonia again since she has already had pneumonia and some lung scarring?**

Sorry to hear that your daughter has experienced this complication from therapy. It's difficult to attribute risk to your daughter based upon not being intimately involved in her care. Therefore, her primary medical team are the best to answer your question. That said, as long as your daughter is not receiving oxygen, has intact lung function (not restricted in activities), and is not receiving medications for her lungs (e.g., steroids), then her risk is probably the same as the risk for other children her age.
- 4. Are NED survivors with heart disease from chemo/rad considered high risk for complications with COVID. My daughter is 30 months since diagnosis of GBM, 15 months since chemo. Do you foresee having a COVID positive history being a factor in disqualifying her or any of our kids for a future trial if the need would ever arise?**

To be cancer free is a great achievement for your daughter, but humbled to hear that she has experienced complications from her therapy. Yes, COVID-19 positivity could be an exclusion criteria from a future clinical trial. However, more information on the epidemiology of COVID-19, particularly in the pediatric cancer patient, may impact COVID-19 positivity being an exclusion criteria.
- 5. My young adult survivor has late-term effects (2 fairly significant heart issues among other issues like metabolism, chronic fatigue). Since young adults generally have less severe cases, is she moderate risk or considered high risk due to underlying conditions.**

Unfortunately, young adult survivors remain at high-risk for treatment-related side effects. The listed side effects would make her at higher risk for severe COVID-19.

## VACCINES, IMMUNITY, TESTING

1. **Since the vaccine is going to be a live virus, immunocompromised persons will not be able to be vaccinated, correct?**

To clarify, the SARS-CoV-2 vaccine will not be a live virus vaccine. The vaccine(s) are being designed to stimulate the recipient's immune system to mount a protective antibody response against the SARS-CoV-2, so that when an individual gets exposed to the virus in the future after receiving the vaccine that individual's immune system would block the virus from causing infection. There are several different vaccines in development, each using either pieces of the virus (genetic material or viral proteins) or inactivated (dead) virus itself as the means to stimulate a protective immune response. Some vaccines are actually using other inactivated viruses to serve as chaperones, delivering the pieces of the SARS-CoV-2 virus to places in the body where immune cells are found. Realistically, there likely will be different vaccines both approved and available to use in the future. As long as each is safe and effective, then having different vaccines is advantageous for achieving herd immunity by vaccinating the world's population.

2. **What would happen to a child who has B-cell ALL, would they be getting vaccinated while in maintenance?**

Yes. There is less concern about safety of the vaccine, as all SARS-CoV-2 vaccines will be either inactivated virus or components of the virus that will stimulate an antibody response in the vaccinated person. The issue in immunocompromised patients is whether their immune systems will mount an effective response to the vaccine in order to be protected against the virus.

3. **Would my immunocompromised child (ALL) be able to receive the vaccine during treatment?**

Yes, with the caveat that he/she may not have a robust immune response to the vaccine and therefore not be protected against the virus.

4. **If my child has had the Covid-19 virus, is there any proof that they may have immunity against the virus?**

Great question! There are available antibody tests that measure antibody to the SARS-CoV-2 virus. However, antibody tests do vary in sensitivity (how well they actually detect the antibody) and specificity (how well they don't detect the antibody).

Furthermore, availability of such tests is also a factor. Lastly, when your child has COVID-19 and when he gets tested in the future may impact results. That is, the longer the time in between having the infection and testing, the lower the antibody levels are in the body. As we don't have great data on how high the antibody level needs to be in a person to confer protection against getting the virus again. Finally, it also depends on how well your child's immune system is functioning to make antibodies.

5. **Our Cancer Kid tested positive for Covid-19 with no symptoms. How prevalent are false positives?**

Great question! No test is 100% sensitive (true positive for what is being tested) and 100% specific (true negative for not having what is being tested). Therefore, your child may either have had a false positive (2-10% chance depending upon the test used), is an asymptomatic carrier, or has yet to develop symptoms. Therefore, your child should be

quarantined for 14 days starting at the time the test was taken and monitored for signs/symptoms of COVID-19. Asymptomatic carriage of the virus is quite common (~40% incidence) and is a primary reason for the pandemic. Therefore, the recommendation to quarantine. Of note, most people exposed to COVID-19 usually develop symptoms within 5 days, but sometimes up to 14 days.

6. **If kids can shed the virus for weeks, that means they can infect others for weeks?**

Yes, that is correct. However, there have been no studies to define infectivity with respect to how long a child sheds the virus. There likely are several factors that affect infectivity, especially viral load. So, the higher the viral load, the greater infectivity risk. Typically, the farther away from having the infection, the lower the viral load. So, despite shedding the virus, the lower the viral load is over time.

## **RETURNING TO SCHOOL, SOCIAL DISTANCING, HOSPITAL EXPERIENCE**

1. **We have been instructed that we are not to open our social circle, however, we should send our children to school? Can you please put this into perspective?**

In general, returning to school for children is challenging. Many factors like the prevalence of the virus in the community, what plans the school has with respect to minimizing exposure among students (e.g., mask wearing, social distancing, cohorting), and parents' means (i.e., ability to stay home from work) and comfort level sending children to school are some considerations. Therefore, there is no universal answer to provide for families and the risk of viral transmission at school will not be zero. Although we do know that most children tend to experience mild or no symptoms from SARS-CoV-2, children can spread the virus to other children and to adults. Therefore, there will need to be flexibility with respect to school attendance in so far as a combination of both physical and virtual attendance. For example, when the viral prevalence is low and assuming the school has reasonable policies in place, then physical attendance will be permissible. When viral prevalence in the community or school is increasing, then transition to virtual learning will be necessary.

2. **We have been so cautious with our child (and us) as he has been going through treatment for ALL (currently about to start IM1 or Blinatumomab)- if his grandparents are feeling well and we are outside, can he hug them?**

Having a child with newly diagnosed cancer during a pandemic is extremely difficult. Just as important as the chemotherapy that your child is receiving is the love and support that he needs from his family. As long as his grandparents have not been exposed to COVID-19, don't exhibit any symptoms (fever, cough, shortness of breath, vomiting, diarrhea, loss of taste or smell, myalgias), and wear a mask along with everyone else in the room (<10 people) who similarly haven't been exposed or exhibit symptoms, then a hug is fine. Doctor's orders!

- 3. I have had terrible experiences in the hospital. Hospital staff tells us time and again about their vacations. We are forced to swab for every admission but the staff is not. This seems very hypocritical. What should we do? My son is really struggling emotionally because of the harsh policies that the hospital staff doesn't seem to have any respect for. He is especially struggling with the number of swabs and not having both parents in the hospital.**

Sorry to hear about your hospital experience. Different hospitals have different policies for SARS-CoV-2 screening and the number of visitors depending upon community prevalence of the virus. Usually hospitals will have a policy in place for the need for repeat screening based upon when the child was screened and if he/she has not had exposure or new symptoms. For example, no need to rescreen if a child was tested in the past 21 days and has not been exposed to COVID-19 or had new symptoms.

## **SPECIFIC MEDICAL QUESTIONS**

- 1. For children who have received Car T 19, have B cell aplasia, and are dependent of IVIG infusions for immunity, do you have any thoughts or recommendations for this very susceptible sub-population of immunocompromised kids with cancer? Part B. Do you foresee years before there is any immunity against COVID- 19 in IVIG?**

A. Yes, you are correct with respect to susceptibility of infection post-CART cell therapy. Continuing IVIG and good personal hygiene, taking appropriate prophylaxis, and adhering to the CDC recommendations are important. Unfortunately, there is no approved antiviral prophylactic medication against SARS-CoV-2. That said, there are some early studies looking at remdesivir for this indication.

B. Great question on the immunity against SARS-CoV-2 conferred by IVIG. Yes, if IVIG is the product. As IVIG is derived from pooled plasma from hundreds of donors. Therefore, there is no high protective antibody against most viruses. However, convalescent plasma from donors who have had COVID-19 is currently in use and being studied for efficacy. It is possible that the product could be helpful given it has a higher level of protective antibody against SARS-CoV-2. Lastly, future products may be manufactured (recombinant antibodies) that could help confer protection against or used as therapy for COVID-19.

- 2. My son is 2.5 years post-transplant for HR ALL with a PDGFRB mutation. He failed induction and needed Car-T to reach remission prior to his mix match cord transplant. Following transplant, he had a higher than normal rate of infections/hospitalizations. My question is regarding GVHD flares in response to children with COVID-19. Are**

**transplant children experiencing cytokine storms when fighting COVID-19? If so, are the storms causing GVHD flares?**

Congratulations to your son who has been there so much! Your question is a good one, and I will answer it in three parts. First, GvHD itself and the immunosuppression used as therapy are risk factors for viral infections, in general. Furthermore, viral infections can induce GvHD flares. Given these knowns, one would assume that SARS-CoV-2 could cause GvHD flares in hematopoietic cell transplant patients. Second, patients with severe COVID-19 have experienced cytokine storms from SARS-CoV-2. These patients' immune systems become hyperactive and produce so high an inflammatory response that it is difficult to reverse the process. As mentioned in the webinar, the virus itself and the immune response to the virus underlie the reason for COVID-19. All that inflammation in the lungs and throughout the body in the case of cytokine storms. Therefore, patients with severe COVID-19 and cytokine storm are actually receiving similar immunosuppressive therapies like tocilizumab that we use for cytokine storm after CAR-T cell therapy. Lastly, we don't yet have enough published data on COVID-19 induced cytokine storms in children who have received a transplant. That's actually, good news. As it suggests that few transplant children actually experience COVID-19 induced cytokine storms. The bad news is it probably will happen in some children and it will be difficult to treat.

**3. Sorry what is the syndrome called that develops after that affects the heart?  
Multisystem inflammatory syndrome in children (MIS-C)**

---

***About Solving Kids' Cancer***

Founded in 2007 by two fathers who lost their children to cancer, Solving Kids' Cancer® (SKC) is a nonprofit organization dedicated to significantly improving survivorship of the deadliest childhood cancers by finding, funding, and advocating for breakthrough treatment options. Headquartered in New York City, SKC's impact is now worldwide with clinical trials launched across the US and throughout Europe. [www.solvingkidscancer.org](http://www.solvingkidscancer.org)

***About Momcology***

Momcology® is a national community-based organization directly serving caregivers of children with cancer through facilitated peer support programs, information distribution, and engagement in projects and programs that address the ongoing needs of families affected by pediatric cancer from diagnosis, through treatment and into survivorship or bereavement care. [www.momcology.org](http://www.momcology.org)

***About Friends of Karen***

Friends of Karen, founded in 1978, provides vital and comprehensive support for New York Tri-State region families caring for a child with cancer or another life-threatening illness, from diagnosis through treatment. The Organization's family-centric approach offers a blend of financial assistance, illness education and supportive counseling, provided at no cost to families. All services are delivered by Friends of Karen's experienced team of social workers, child life specialists, and expressive-arts therapists. With

an individualized plan of support for each family to meet their needs, the Friends of Karen's overarching goal is to enable each member of the family to remain stable, functioning and able to cope during a time of intense family crisis. Friends of Karen is top rated from Charity Navigator, the BBB of Metropolitan New York, and received a Gold Seal of Transparency from GuideStar. [www.friendsofkaren.org](http://www.friendsofkaren.org),

***About The Max Cure Foundation***

The mission of The Max Cure Foundation, Inc., is to fund research for the development of pediatric cancer drug therapies including the discovery of less toxic treatments for children with cancer as well as seek to reduce the incidence rate of pediatric cancer diagnoses through prevention initiatives; to financially assist low-income, military and first-responder families battling cancer in their children; and pursue legislative and regulatory changes that seek to benefit children with cancer and at the same time, raise awareness to the needs of those fighting pediatric cancers. [www.maxcurefoundation.org](http://www.maxcurefoundation.org)

*Thank You*

