



This Q & A article is from BDSRA's "Ask An Expert" Facebook Chat in the BDSRA Closed Facebook group for parents and caregivers.

*Please note: the information contained in this material is intended to provide basic information to Batten families and caregivers. It is not intended to be, nor is it, medical advice for individual children. Parents and caregivers should consult the patient's physician prior to changing medication, medical treatment or daily activities.

"All Things COVID-19"

Featured Experts:

Dr. Erika Augustine, MD, a pediatric neurologist
Dr. Amy Vierhile, DNP, a pediatric nurse practitioner,
Dr. Heather Adams, a child psychologist/neuropsychologist
University of Rochester Medical Center
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Hello to everyone in the Batten community! We hope everyone is keeping well, staying safe. Everyone here at the University of Rochester Batten Center (URBC) is thinking a lot about all of the families affected by Batten disease, and we want to stay connected with you especially during this time. Please don't hesitate to call or email us. We'll post our contact information at the end of this introduction, and again at the end of this session.

The general goal of this "Ask-an-Expert" live chat is to hear from you and to answer your questions about the impacts of COVID-19 on your affected child and your family, and how you are coping with all the changes to daily routines, services, school, etc.

Here on the call today from the URBC are: Dr. Erika Augustine, MD, a pediatric neurologist; Dr. Amy Vierhile, DNP, a pediatric nurse practitioner, and Dr. Heather Adams, a child psychologist/neuropsychologist.

Dr. Augustine will begin with a very brief overview of what is known about COVID-19 and any special considerations related to children with neurologic disorders. Then we'll dive right into your questions.

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Q: What is COVID-19?

A: Coronavirus disease 2019 (COVID-19) is a respiratory illness that can spread from person to person. This is an infectious disease caused by a newly discovered coronavirus. In January 2020, The World Health Organization created a 5-minute video explaining early information about the coronavirus outbreak. <https://www.youtube.com/watch?v=mOV1aBVYKGA#action=share>

Q: What are the symptoms of COVID-19?

A: People with COVID-19 have had respiratory illness ranging from no symptoms to severe illness. The main symptoms include:

- fever
- cough
- shortness of breath

Q: What do we know about children and COVID-19?

A: “While some children and infants have been sick with COVID-19, adults make up most of the known cases to date. The symptoms of COVID-19 are similar in children and adults. However, children with confirmed COVID-19 have generally shown mild symptoms. Reported symptoms in children include cold-like symptoms, such as fever, runny nose, and cough. Vomiting and diarrhea have also been reported. It is not known yet whether some children may be at higher risk for severe illness, for example, children with underlying medical conditions and special healthcare needs.”

Sources – CDC and World Health Organization.

Additional general information about COVID-19 and children can be found here:

https://www.uptodate.com/contents/coronavirus-disease-2019-covid-19-and-children-the-basics?search=coronavirus-disease-2019-covid-19-the-basics&topicRef=126678&source=related_link

Q: What can I do?

- Stay home
- Wash your hands often
- Avoid close contact with people who are sick or might be sick
- Clean and disinfect frequently touched surfaces
- Recommendations from the Child Neurology Society can be found here: <https://www.childneurologyfoundation.org/cnf-cns-joint-official-response-to-covid-19/>
- Recommendations from the Epilepsy Foundation can be found here: <https://www.epilepsy.com/article/2020/3/concerns-about-covid-19-coronavirus-and-epilepsy>
- Recommendations from the CDC for individuals at high risk can be found here: <https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID19-What-You-Can-Do-High-Risk.pdf>

Q: Where can I find reliable information?

- CDC <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
- World Health Organization <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>



- Your state health department. Find your state's health department website here: <https://www.cdc.gov/publichealthgateway/healthdirectories/healthdepartments.html>

Note – check dates on websites. Some information and recommendations change frequently. Use the most up to date information.

Q: Our physical schools have closed for the year due to the virus. School is no longer providing speech therapy OT PT TVI and OM. What are things I can do at home?

A: The first thing to do might be to take a look at your child's Individualized Education Plan (IEP) and see what services are listed. The school district should still have some contacts available who you can reach out to. We have heard of families arranging through phone or videoconferencing to either have their child's service provider offer some help into the home, and/or coach the parents on what services can be continued at home, facilitated by the parents. There might also be technology that your child uses at school, that perhaps could be dropped off at your house for use during this time. Our local school district has been delivering chrome-books to kids who don't have them!

Some of the services that can be continued remotely or through coaching may be dependent upon your state's decisions about extending special education services during this time - some states are making sure that this continues to the extent possible, others have introduced some flexibility in interpretation of the laws related to special education service provision

Q: I am having issues with our district because they are offering nothing for special ed chrome books aren't a substitute for a TVI, physical therapy, orientation and mobility, etc

A: Your state should have an office that deals with educational rights/educational advocacy for families; the state's Department of Education website might also have some guidance. There should be state-level guidance on how special ed services should be addressed during this time, and the school district is required to be in compliance with this. However, even if the district or the state are not able to formally help, are you able to contact the individual providers at school who your child worked with, to ask them what you can be doing at home? Will they provide you with copies of progress reports or intervention plans that can help guide you to implement services at home?

Q: Is Covid-19 harder for our kids to fight off?

A: People who have active chronic illnesses may be at higher risk from COVID-19. Overall, including those with risk factors, children seem to have a disease course that is less severe than that of adults. Prevention is the key factor, as we have all been hearing. The Child Neurology Society has put together some information that might be helpful in thinking about risk and what to do:

https://www.childneurologyfoundation.org/cnf-cns-joint-official-response-to-covid-19/?fbclid=IwAR3UCrdpyd6W3T8MhN2A3m5dNem_TWgHMQA1dZB9XLIFdHnjpwKM-zH-Fo



Q: I am an essential worker and work with the community, my concern is carrying this home to my children...what extra precautions can I be taking?

A: Thank you for your work with the community, especially with those in greatest need right now. Your organization may have issued some recommendations regarding self-monitoring for symptoms and when to consider not reporting to work. It is important to review these guidelines, if developed, along with any recommendations for personal protective equipment as you conduct your work. Some other considerations: 1) wearing clothes that are easily washable in hot temperatures rather than dry-clean only or cold-water wash items, 2) changing clothes when coming into your house, 3) washing hands before and after (and during) times when you are working out of the home, 4) disinfecting surfaces at home that are touched often, including doorknobs.

Q: What are some rules and guidelines you recommend for families that have in home help (such as Aides, Nurses, Respite providers, etc.) to prevent potential spread or infection to the Batten child?

A: Many families really rely on their child's nurses, aids and other respite workers to care for their child. Everyone who enters the home should be familiar with the symptoms of COVID-19 and not report for a shift if they have a fever, body aches, cough or excessive fatigue. Some families self-employ their child's caregivers and they may want to ask them to report these symptoms directly to the parents. Other families have caregivers who work through an agency and in those instances, any illness on the part of the caregiver should be reported to their employer. Some families also consider asking providers that come to the home questions about how many other families they support or provide services to (in the home) to help with thinking about risk.

Q: I am concerned about the autoimmune component with Batten and Covid-19. I have noticed a decrease in functionality in my child whenever they get a major infection. Is this a possibility with this illness even if they only presents with mild symptoms?

A: As you mention, there is an autoimmune component to Batten disease, where antibodies that should help in fighting off infection can attach to the surface of the body's own cells. We are still learning more about what these antibodies mean to individuals with Batten disease. Also, the decrease in function that you see with other infectious illnesses, can happen with many infections, including COVID-19. Continuing regular activities or respiratory therapies if already using them can be important at times like these, along with prevention through handwashing, cleaning surfaces, and distancing from groups or those who are ill.

Q: Are there any reported cases of COVID-19 infection in Batten patients and maybe outcome?

As of today, we are not directly aware of individuals with Batten disease who have been reported in the literature or news who have had COVID-19. It is important to remember that children can be asymptomatic and still have and spread the virus. Also, testing availability is limited in many places, so not every person with the disease has had testing to confirm. Important risk factors to consider: 1) living in a long-term care facility, 2) having known lung conditions like severe asthma, 3) regular exposure to



smoking, 4) prolonged use of steroids or other immunosuppressant medications, 5) diabetes. More information can be found on this page from the CDC: https://www.cdc.gov/coronavirus/2019-ncov/downloads/COVID19-What-You-Can-Do-High-Risk.pdf?fbclid=IwAR3UCrdpyd6W3T8MhN2A3m5dNem_TWgHMQA1dZB9XLIFdHnjppwKM-zH-Fo

The Epilepsy Foundation has written a helpful summary on COVID-19 and Epilepsy which may address some questions. https://www.epilepsy.com/article/2020/3/concerns-about-covid-19-coronavirus-and-epilepsy?fbclid=IwAR1CuWZF-sTxnXyUw_30i24Vq0kNCJS4vK6LqtGN-309xhf3P1jiN8X2_Q4

Q: We realize that a lot of affected individuals might be struggling to adapt to the big and sudden changes in their routines.

A: As much as possible, we encourage folks to keep to a schedule as much as possible, including the usual sleep patterns for bedtime, waking up time, mealtimes etc. (this can be especially important for seizure control). Even if children are not attending school or their other usual daytime programming, if it is possible to have a schedule at home that seems to mirror the usual schedule, e.g., if school starts in the morning with a song or a game, try to do that at home; etc. We know this is "easier said than done" as parents are also adapting to their own changing schedules.