

March 11, 2020

RE: 2020 Aicardi Syndrome family conference

Dear families and friends of children with Aicardi syndrome:

For many years your organization has been so kind to invite me and other doctors and scientists to the family conference that you hold in July every two years. I learned this week that this year the conference was canceled because of the coronavirus outbreak, and I know that this is very disappointing to many of you. I will also miss participating and seeing many of you again and meet new families. However, I believe this is the right decision. Watching the new coronavirus disease outbreak become more and more widespread, I had intended to contact the organizers of the Aicardi Syndrome Family Conference on Monday to express my concern for the health of your children and families and recommend that they consider canceling this year's conference planned for July 2020. I was relieved when they notified me before my own intended message that this wise decision had already been made. I think it is the absolutely correct action to take under the circumstances! Currently, almost every medical conference in the next few months has been or is also being canceled. We as physicians are rightfully being restricted from traveling and attending large gatherings of more than a small number of people (15 at some institutions, more or less at others). As you have seen on the news, major other events are also being canceled, and in some schools and colleges, classes are being suspended.

The current coronavirus disease outbreak is rapidly spreading across the world and we are just at the beginning of what will be the extent of the epidemic in the United States. It has just recently been declared a pandemic by the World Health Organization. Considering this, I think there is a reasonably high likelihood that it will not have ended by July 2020. We can of course not fully predict this, but it is my opinion that the risk of traveling and gathering in a large group is best avoided for your families. While it is thought that in general children are less severely sick when they contract the disease, many of your girls have health issues and perhaps certain treatments that can weaken their immune defenses. This puts them at higher risk for the severe forms of COVID-19 disease, as we know that primarily (although not only) those who are the most ill and have died from COVID-19 are either older or have other health issues. Because of this, while I realize that it must be very disappointing not to be able to connect at the conference this year, I understand and support your organization's decision. I will also explore some different online ways to share information and updates with all of you.

I wish you all good health, especially during these next few months and I recommend you follow the guidance from your local health authorities, your healthcare providers, the Centers for Disease Control on this website: (<https://www.cdc.gov/coronavirus/2019-nCoV/index.html>) with links to frequently asked questions. Many hospitals and medical schools also have good information and advice on their websites.

With sincere regards,



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