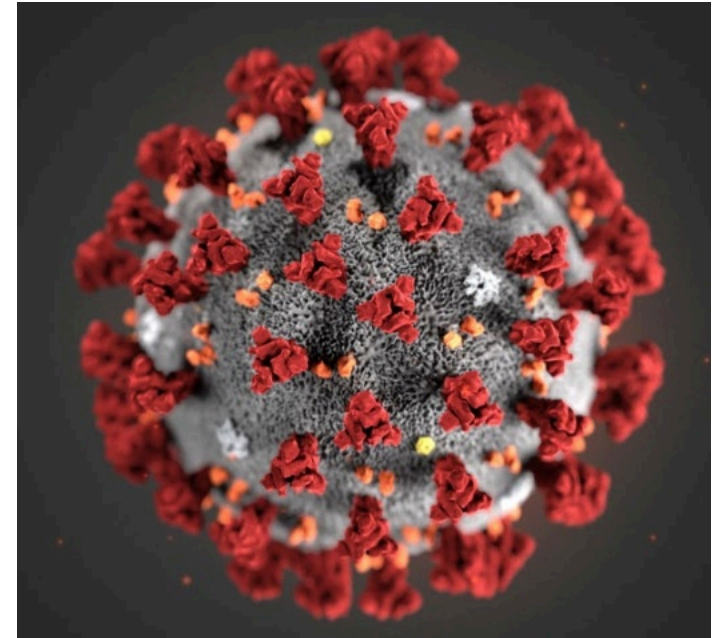


COVID-19

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NEURODEVELOPMENT IN RARE DISORDERS



What is COVID-19?

- COVID-19 is a type of coronavirus leading to respiratory illness that was first seen in humans in December 2019.
- The virus mostly spreads through close contact with others such as droplets from coughing or sneezing or touching mutual surfaces. The virus may also spread through airborne transmission.
- A COVID-19 diagnosis can only be confirmed through laboratory testing. There is currently no vaccine or approved treatment.

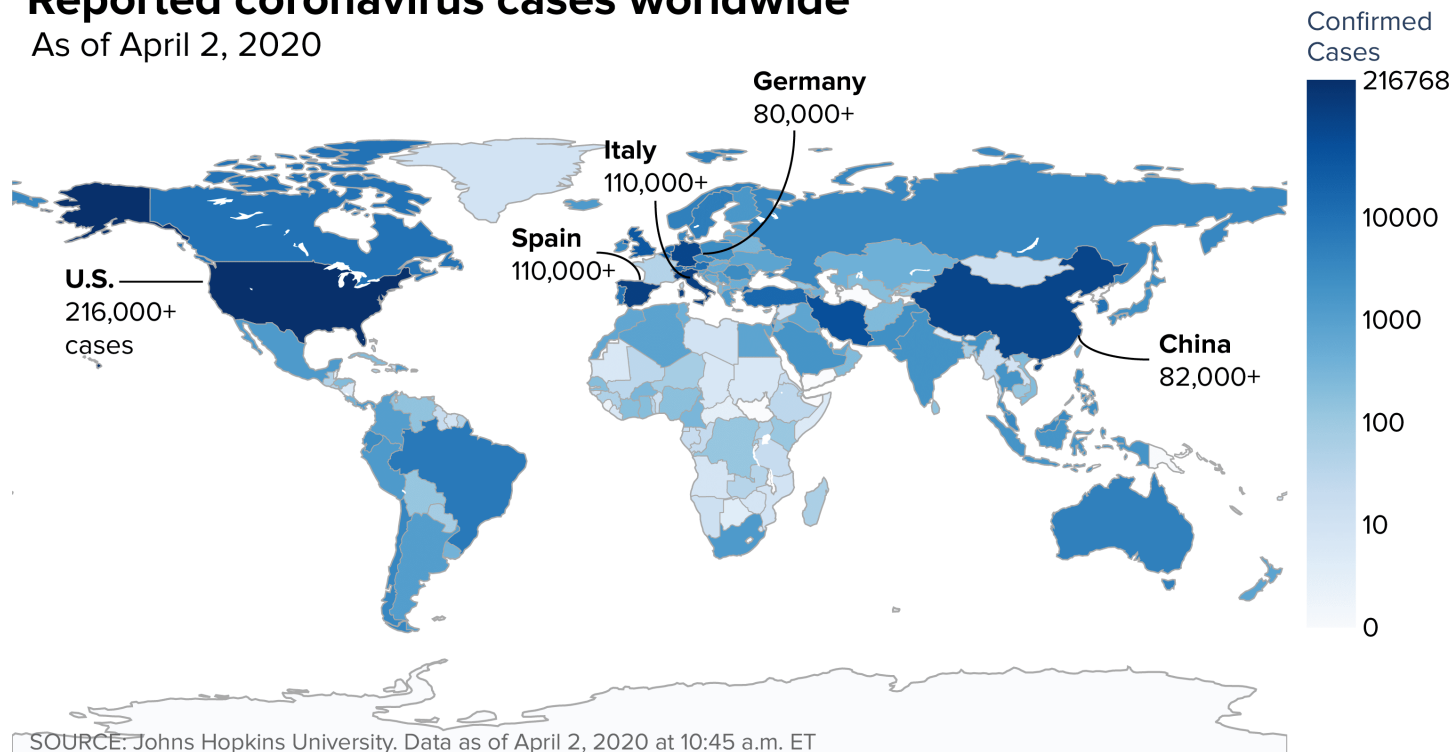
What is COVID-19?

- Symptoms of COVID-19 emerge within 14 days of exposure, though many cases present with minimal or no symptoms. This is especially true in children.
- Symptoms of COVID-19 range include:
 - Fever
 - Coughing
 - Shortness of breath
 - Sore throat
 - Runny nose
 - Body aches
- In some cases, patients may experience more severe respiratory symptoms or kidney failure.

COVID-19 Cases

Reported coronavirus cases worldwide

As of April 2, 2020



Total number of confirmed cases:

- Worldwide: 1,054,434
- USA: 256,952

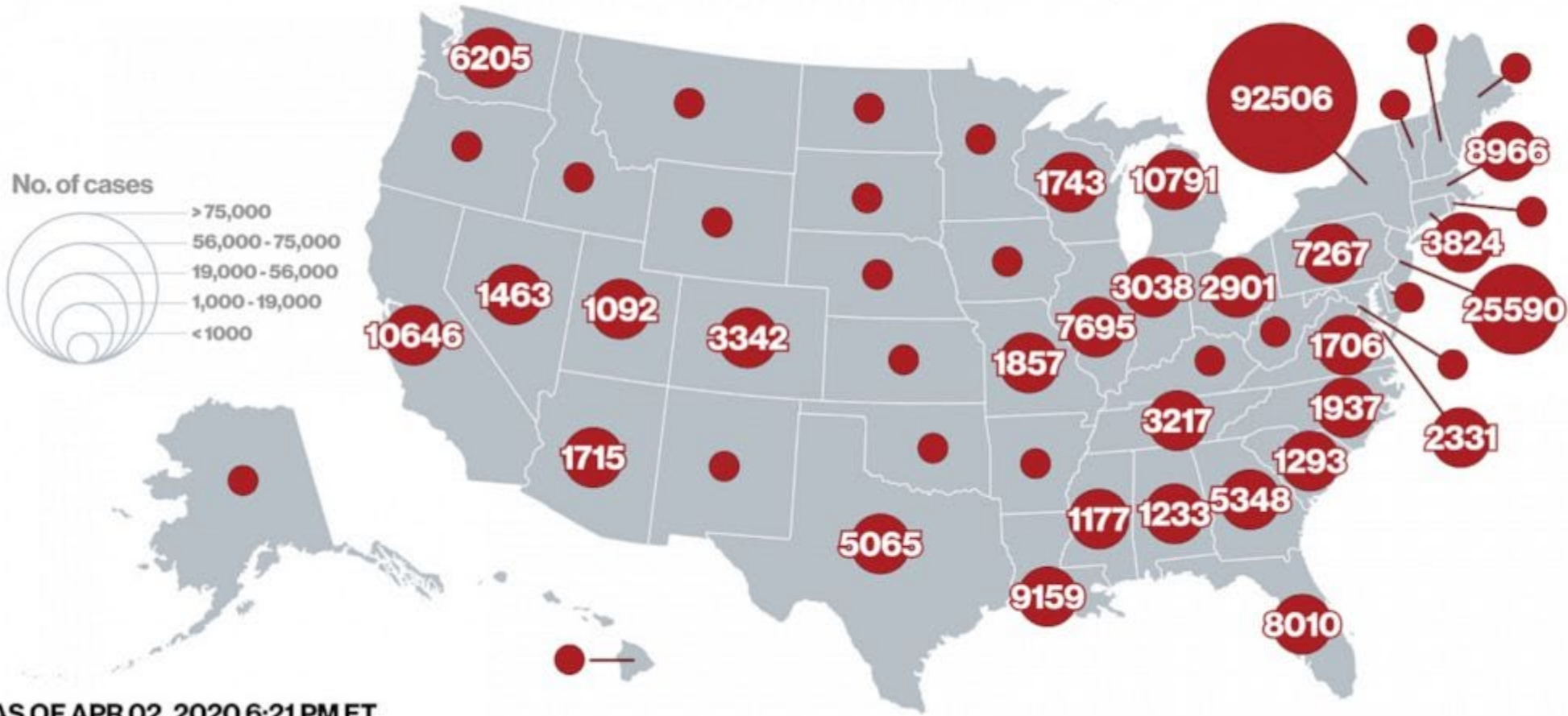
Total number of serious/critical cases:

- Worldwide: 38,755
- USA: 5,756

Total number of deaths:

- Worldwide: 55,720
- USA: 6,552

U.S. CORONAVIRUS CASES



AS OF APR 02, 2020 6:21 PM ET

SOURCE: JOHNS HOPKINS CSSE

*Does not include individuals repatriated to the US from Wuhan, China, and from the Diamond Princess cruise ship.

COVID-19 in children

- Symptoms in children are similar as those seen in adults and include:
 - Fever
 - Cough
 - Sore Throat
 - Difficulty breathing
 - Diarrhea

- It is currently believed that the majority of children affected by COVID-19 don't show any symptoms or mild symptoms and infections in children are less common.

- However, more research is needed to better understand how the virus affects children with underlying medical conditions.

1

Krabbe patients naturally have a lot of secretions and may develop shallow breathing. As a result of these underlying factors, Krabbe patients may have more respiratory complications and develop pneumonia due to this virus.

2

Krabbe patients who were recently transplanted and are still on immunosuppressive drugs should take extra precautions.

3

Parents should monitor and adjust (if necessary) fluid intake to avoid dehydration.

4

If a patient with Krabbe disease were to be hospitalized for COVID19, they should not be given an excess of IV fluids and intubation should be considered carefully depending on the degree of disease progression of the child.

5

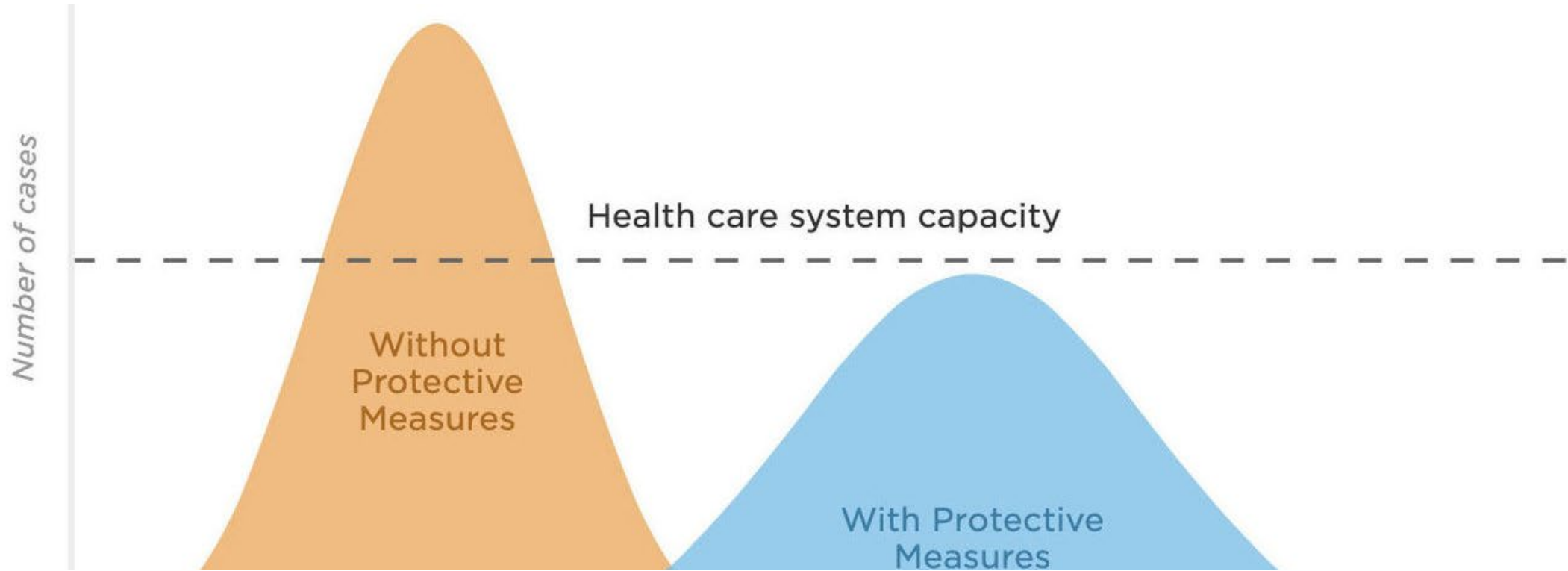
Parents should contact their physician regarding any abrupt change in temperature or worsening of respiratory symptoms.

COVID-19 in Krabbe patients

Taking Precautions



- Wash your hands frequently for at least 20 seconds
- Avoid touching your eyes, nose, and mouth
- Clean frequently used surfaces like phones, door knobs, and light switches often
- Wear a mask if you are caring for someone with respiratory symptoms
- Stay home as much as possible
- Minimize all visitors into your home
- If you need to leave your home:
 - Stay at least 6 feet away from other people
 - Go out during off-peak hours
- Contact your physician if you or your child are experiencing any symptoms.



Avoid close contact with others

Questions from Families

Treatment of symptoms is critical in providing the best quality of life for our Krabbe children. Most specifically, therapies such as PT and OT, are critical in maintaining our children's overall health.

With in home therapies through Early Intervention suspended, is it appropriate to continue outpatient therapies at this time? What factors should be considered when weighing the benefits verses risks of going to these therapies out of the home?

Due to the pandemic, it's my understanding that we should not travel to our yearly/quarterly/etc. appointment for our follow-up.

Although this pandemic is frightening, how do I feel "ok" with putting my child's life-threatening illness on hold? My "check-ins" or follow-up appointments allow me to understand further where my child is in the disease....if things are stabilizing, if they're getting worse, if a medication needs to be changed, etc.

Are there any medications you recommend that we have on hand at home in preparation that our child does get this, and we can give it to them right away and avoid hospitalization or to lessen the symptoms?

Thank you all for attending the KrabbeConnect Webinar

FROM THE PROGRAM FOR THE STUDY OF NEURODEVELOPMENT IN RARE
DISORDERS

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