March 31, 2020

Dear SYNGAP1 Families and BTG Supporters,

First, we want to thank SYNGAP1 Community Members for your compassion and commitment as we continue to encourage one another, share resource information and provide a voice for people diagnosed with SYNGAP1 and their families. We recognize that the current situation is unlike anything, any of us, have faced in our lifetimes. The novel coronavirus (COVID-19) pandemic has impacted virtually every aspect of our daily lives, leaving many families feeling unsettled and uncertain about the coming months. Thus, we want to assure you that our primary concern continues to be the health and well-being of our global SYNGAP1 Community.

We are working closely with our colleagues in the rare disease space, including federal and state authorities, to help ensure SYNGAP1 Community concerns and needs are being heard and addressed. We are in the process of finalizing a list of community resources, along with general guidance and information about COVID-19 provided by the CDC and our Centers of Excellence health experts. All information and updates will be posted on the BTG website page, COVID-19 Resources. We will continue to monitor the on-going pandemic situation in collaboration with the rare disease community, government and community leaders to keep everyone informed of information relevant to our community.

On a related note, a situation was brought to our attention by one of our Australian SYNGAP1 family’s related to COVID-19 treatment guidelines in the UK. Hospitals in the UK recently received the National Institute for Health and Care Excellence (NICE) Fragility Scale COVID-19 Guidance for Treatment. The original text within the issued guide pertained to COVID-19 treatment guidelines for individuals with intellectual disabilities and cerebral palsy, which would have excluded patients from receiving priority COVID-19 treatment in the UK, based upon their disability.

Upon receiving this information, we reached out to one our UK SYNGAP1 families, who quickly addressed the concerning guideline noted with the UK Parliament. As a result, 24-hours after the issue was presented to the UK Parliament, the National Institute for Health and Care Excellence (NICE) began working on clarifying the Fragility Scale guidance that would have excluded individuals with certain disabilities from priority COVID-19 treatment in the UK. Please read the following statement published by NICE on March 23, 2020:

[statement from NICE]
@NICEComms -
"We welcome the recent clarification that the Clinical Frailty Score should not be used in certain groups, including those with learning disability and cerebral palsy (scfn.org.uk/clinical-frailty-scale), which we will reflect in an updated version of our guideline. (5/5): NICE Tweet Announcement

We are very thankful to all BTG SYNGAP1 families, who remain committed to protecting the rights of those affected by SYNGAP1, who continue to work with us to ensure government and medical guidelines protect our loved ones. This is especially important now, when many with disabilities are most vulnerable.

As for COVID-19 treatment guidelines for people with disabilities here in the United States, we are pleased to share the following - HHS’s Office of Civil Rights issued this guidance, published on March 28, 2020.

The HHS guidance specifies:
“persons with disabilities should not be denied medical care on the basis of stereotypes, assessments of quality of life, or judgments about a person’s relative “worth” based on the presence or absence of disabilities. Decisions by covered entities concerning whether an individual is a candidate for treatment should be based on an individualized assessment of the patient based on the best available objective medical evidence."

2020 Bridge the Gap – SYNGAP ERF Events Update

We appreciate your continued commitment and support. Your generous contributions of time and money have enabled us to fulfill BTG’s mission to support SYNGAP1 families through our advocacy and education programs, build collaborations with a diverse group of SYNGAP1 stakeholders and accelerate research for better SYNGAP1 treatments.

UK Family Education Meet Up
University of Edinburgh, Scotland, UK
June 6, 2020
We currently still plan to hold the Family Meet Up on June 6th. We will continue to follow public health policy guidance and will notify interested attendees should we need to postpone and reschedule due to the COVID-19 pandemic.

BTG SYNGAP1 Golf Classic
Cinco Ranch Gold Club, Katy, TX
September 17, 2020
The Golf Classic has been rescheduled for September 17, 2020. More details will be provided later this summer.
Currently, there are no schedule changes to report for **BTG’s International SYNGAP1 Scientific Conference, FDA/BTG EL-PFDD Meeting** or **BTG Industry Roundtable Meeting**. We will provide scheduling updates if needed.

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<thead>
<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
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<tr>
<td>International SYNGAP1 Conference</td>
<td>November 17 – 19, 2020</td>
<td>Bethesda, MD</td>
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<tr>
<td>FDA – BTG SYNGAP1 Externally Led - Patient Focused Drug Development Meeting</td>
<td>November 19, 2020</td>
<td>Bethesda, MD</td>
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<tr>
<td>BTG - SYNGAP1 Industry Round Table</td>
<td>November 20, 2020</td>
<td>Washington, DC</td>
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In closing, we want to thank our amazing SYNGAP1 Community, for your unwavering support. Without you, we would not be where we are today, as an organization. As we continue to move forward during uncertain times, we want you to know we stand beside you, in support of SYNGAP1 families and all SYNGAP1 communities. Please contact us should you have any questions, need assistance with community resources or COVID-19 information.

May God bless each of you and your loved ones in these very trying times. Be well and stay healthy.

Warmest Regards,

*Monica Weldon*

Monica Weldon  
President/CEO/Founder  
Bridge the Gap - SYNGAP Education and Research Foundation