



**CDKL5 ALLIANCE
ZOOM LEADERSHIP MEETING MINUTES
MARCH 21, 2020 @12pm EST**

Members Present:

Antonino Caridi, Carol-Anne Partridge, Rick Upp, Natalie Ladly, Norberto Fischer, Katheryn Elibri, Patric Benz, Richard Li, Jainu Jogan

WELCOME - CHAIR

Antonino welcomes everyone to our first virtual meeting of our leadership board. We discussed COVID-19 and the impact it is having. Specifically how it will certainly cause IFCR to post-poning Family Conference in Houston planned for June. At that conference, the Alliance will present the leadership board and it's function to all families.

DISCUSS THE 4 TASKS OF THE LEADERSHIP BOARD

In Antonino's executive summary, he presented the 4 tasks of the leadership board which we will elaborate on as a group.

1. Recruit as many patients as possible to each National Family Organization (NFO)
 - a. Plan to create pamphlets and circulate to hospitals to create awareness, present to university PHD students, etc.
 - b. We want to improve our reach in each country
 - c. Antonino asked if it is possible to upload pamphlets from each country to portals on the Alliance website so everyone can access them? Carol-Anne said we probably can but it is a basic website and it will need development. The UK is no longer paying to host/develop the website so Carol-Anne will get a quote and perhaps all National Family Organizations can contribute to fees.
 - d. Jainu wonders if we can use another website which is already developed (an established NFO website) and Carol-Anne said that wouldn't be fair and it wasn't what Majid wanted.
 - e. Antonino agreed that the Alliance website is intended to be the first point of reference for new patient families, especially for countries that don't have their own NFO.
2. Find hospitals to be future CDD clinics / sites to host clinical trials
 - a. Want to try to find at least one hospital in each country

- b. IFCR is a leader in this with 8 centres of excellence, in Italy they have 2 centres hosting the Marigold Study, the UK is connected to a hospital, and Switzerland/Germany/Austria has a team of excellence between them, Canada has two RETT clinics that will see CDKL5 patients but are working on creating something specifically for CDD patients, etc.
3. Get all CDD patients in a national or international registry
 - a. There was some confusion over which registry we should be promoting to our families. LouLou has a registry they are working on, Australia has the National History Study, IFCR has CDKL5 Connect which can be uploaded onto each countries website, etc.
 - b. Rick is going to figure out where we stand with these registries so we can all be on the same page and present a united front.
4. To be discussed at the next meeting

OTHER BUSINESS

- Antonino, Rick & Carol-Anne are going to get together to prepare rules and expectations of the role of the Alliance moving forward. Once these documents are complete, they will circulate to the group and we can set a date for our next meeting.
- Kathryn has been given the task of looking into developing Africa since we have no one diagnosed with CDD in the continent. She is excited about the role but says it will be challenging based on differences in economy and culture. Epilepsy is stigmatized in Africa which may be why there is no one diagnosed and for this we must tread carefully. She has a plan on how to start and has some connections in Africa but asks the group to contact her with any additional contacts.
- Carol-Anne suggested we need to give some thoughts to what we want to accomplish in Africa. If we manage to get families diagnosed what happens next? What do we have to gain? What to they have to gain? Is this a worthwhile endeavor? We need to be careful and ensure that we are taking their mental health and ours into consideration because their culture is so different.

TERMINATION OF THE MEETING

The meeting was terminated at 1:20pm EST.

NEXT MEETING DATE: TBD