



CDKL5 ALLIANCE LEADERSHIP BOARD MEETING AGENDA

Saturday, April 10th at 11am EST

Zoom Video Conferencing

In attendance: Heike, Antonino, Natalie, Patric, Rick, Katheryn,

- 1) Welcome
- 2) Situation of the Alliance Manifesto and Letter of Understanding

Brazil, Ireland, Austria (Patric will get in touch) Spain, Holland (can't sign but wants to be involved)(Ireland and Spain may have sent) Hope4Harper will follow our activity but they don't want to sign the letter. We haven't been able to get in touch with Norberto. He was looking for a replacement but we haven't heard back. The covid situation there right now is very difficult so its likely not a priority.

- 3) International eCongress for CDD Families in 2021

This year it was going to be hosted by Switzerland/Germany/Austria but due to Covid they can't host. Due to that the Alliance (Rick, Antonino, CA and Patric) is going to host the eCongress on June 13th. Antonino shares the draft program for the econgress. We hope that we can make this live on the Alliance website on June 13th. There will be a session by specialist from the CDD community, pharma. They will be in English with the option for Subtitles for spanish, Italian, French, german, Russian and Japanese. We will have people post questions and we will get answers and post them afterwards. Katheryn suggests that we have the moderator and speakers be live so questions can be

answered. Due to the time zone difference it makes it difficult because we are +/- 9 hours GMT. This way you can watch it anytime and post questions. The program will be attached for the leadership groups review. Antonino has asked everyone to use "human language" so families can follow. They will see the icons with picture of the speaker and topic and then watch the presentations of their choice. An 'a la carte' conference.

Katheryn says its well rounded and touches on a lot of topics but feels it may be light on concerns of symptoms and management which will be of most interest to families since this is targeted at families. Maybe do separate speeches on key symptoms that can be expanded on. Also on therapies to improve their quality of life now, before the treatments and cure come. Antonino asks for Katheryn to send the main symptoms to be spoken to so Tim can address them. Rick asks if Antonino has reached out to Famida and Helen to give them some direction. Famida is going to reach out to Helen and they will coordinate their presentations. We hope to have all the presentations by middle of May. Heike will send instructions on how to do recordings.

Antonino – our activities, Natalie will talk about our organization with the chairman, secretary, leadership board and general assembly. Manifesto and letter of understanding which unite us with our goals, principles,

4) Alliance program 2021

What are our plans for this year after the econgress? It would be nice to come up with some tasks/goals that would be beneficial to our community. We are pretty well organized in our community but now we can come up with more ideas. We can utilize whatsapp or email. Antonino said that each member of the leasership board should be the bridge between the board activity and their neighbouring countries/associations. So when we work on activities, we channel the information to them.

- 5) Proposal for substitution of 1 Leadership Board Member – Perhaps we approach Spain and ask them if they will take his place. The Spanish group is also becoming the point of reference for Spanish speaking countries (Argentina, Peru, Colombia). If we are in agreement Antonino is going to approach Spain. Since we don't have anyone in South America that is a good alternative.
- 6) Kathryn has found a nurse in Africa who has some children who they think they may have CDD but they have no means to test them. She asked everyone to send hospitals who will do testing from other countries.
- 7) Termination of meeting at 12:03pm EST