



## CDKL5 ALLIANCE LEADERSHIP BOARD MEETING MINUTES

Saturday, January 23<sup>rd</sup> at 11am EST

Zoom Video Conferencing

In attendance: Antonino, Natalie, Rick, Carol-Anne, Patric, Jainu

1. Antonino welcomes the group and wishes everyone a Happy New Year. He acknowledges that it is difficult to work as an organization during covid but we will continue to do video conferencing in place of our semi-annual meetings for the time being.
2. Recap of 2020 Alliance activity:  
In 2020 we accomplished the main goals that we set out for the year. In 2020 we finally found the right wording for our manifesto, and the letter of understanding has been signed by more than half of our national family organizations. Some countries still need to be followed up with but we believe they will all participate. Antonino asks that each of us follow up with one of the outstanding organizations to get the task complete.

Other accomplishment was the clinical trial readiness. We were able to expand the list of hospitals and clinics around the world that will host trials for CDD kids. This list is important and the document that was produced has helped countries that previously didn't have the infrastructure get organized and set up.

Last June we also hosted our first virtual family conference. IFCR did a great job hosting it and we know it was very difficult but it worked. The forum was also hosted virtually in October which was important to our community, so we can be aware of the most recent research and developments for CDD. Antonino has been working with the LouLou foundation to produce some videos. One was the video interview he made with Majid which is available on youtube and there is another one coming with Dan that will be made in multiple languages. Antonino will let us know when that video is available.

In regards to the forum, the virtual platform they used was good. Majid says he is willing to let us utilize the same format if we want to host a virtual 2021 national family conference. Antonino asked Patric if he wants to rethink hosting since we can use LouLou's platform? He suggests that perhaps we do just one day (6 hours) rather than two days. It would be less work and that way we can ensure that we continue to host a meeting for families each year. Patric explains that he can't make the decision alone because he needs to ask the German and Austrian associations. Antonino offers that

members of the alliance can help and share the work if that makes a difference. Patric says that he will ask the other associations and have an answer for us next week.

### 3. Media

The Alliance website can be updated now and filled with all the documents, news, events, photos, and more. The vision for the website is for it to give a broader view of what is happening around the world. It can be documented in Georgian, Russian, English, whatever the mother tongue is for each respective country. It is not intended to duplicate any of the larger websites but for smaller associations it may be a good jumping off point. It shows that we are all working together for our common goal of community.

Carol-Anne is currently receiving information from countries after we asked associations for news and updates last week. The Alliance site has the ability to link back to country's website if they already have one or it can link to associations facebook pages. Or it can act as a website for smaller organizations.

Heike has added some links to news and events on the website. Outside of the website, we have twitter but CA is already hosting 5 other twitter feeds so she would prefer someone else to take that over if they want it to be more active. She acknowledges that we decided not to move forward with a fb group since there are already so many out there.

Heike is going to add the manifesto to the site next week but we need to get some information from South Asia and China because they aren't listed right now. CA also wants to get the links to all the various youtube pages. The videos from Edinburgh are already posted but it would be useful to have them all. It would also be good to have a link with all the centres of excellence listed so people can reference it to see where the closest site is to them, regardless of location. She mentions that currently the "Get in Touch" section isn't working but once we have all the various emails, it will be loaded along with who they are (parent or professional, etc.).

Patric will send the logo to Heike for Switzerland which is missing and get Austria's information sent as well because they aren't on there.

Natalie is going to send an email reminding each organization to send anything they want added and will also remind organizations to send the signed letter of understanding. We are still missing it from Ireland, Holland, Slovakia, France and a few others.

Norberto has been hard to track down. He has been dealing with some family issues so he is looking for someone to replace him in his role in Brazil.