



## CDKL5 ALLIANCE VIRTUAL MEETING MINUTES

The CDKL5 Alliance Virtual Meeting was held on Saturday, September 19th, 2020 at 11am EST.

### **Members Present:**

Antonino Caridi – CDKL5 Italy  
Carol-Anne Partridge – CDKL5 UK  
Rick Upp - IFCR  
Natalie Ladly – CDKL5 Canada  
Patric Benz – CDKL5 Switzerland  
Patricia – CDKL5 Spain  
Maria Ivanova– CDKL5 Russia  
Paula Connolly– CDKL5 Ireland

Natalie apologies for the error on the start time of the meeting. There was confusion with the time zones.

### **1. Partnership Agreement**

Antonino opens and explains that the main reason for the meeting is to discuss the Partnership Agreement. He asks what the group's thoughts are on the revised agreement.

Patricia is waiting to look at it with the board next week but doesn't foresee any issues.

Canada is having their lawyer review it because they want to make sure they are protected and it doesn't impact their charitable status.

Patric wonders if we need the document because it outlines what already exists.

IFCR have concerns about signing a contract and how it would affect their charitable status. The reaction got worse as the week went on. IFCR can agree to the terms but there is a strong concern about signing a legal document.

Paula (said she hasn't looked further into it aside from reading through it. She isn't sure if she is keen on signing anything legal as we don't know where we will be in 5 years. If the larger groups decide to go forward, then they will look into it further.

Rick explained that the contract will be interpreted according to the law of one specific country (likely the country of origin) which may also cause some issues. Carol-Anne points out that is

isn't a charitable organization that is being created. It is just a set of rules to abide by to unite the group.

Antonino explains that the reason they originally created the document was to make the Alliance more formal so that it was more organized. He understands that because the document is structured like a contract it could cause issues for some organizations to sign. He suggests that perhaps we make a manifesto that keeps the spirit of the document alive and outlines our objectives, principles and our aim as an organization. We can leave the more complicated rules and articles out of it. That way there are no legal implications.

Everyone agrees that a manifesto or memorandum of understanding is something that all the groups can agree on and be part of.

Antonino proposes that him Rick and Carol-Anne will now prepare the manifesto and once it is finalized, we will circulate it and get an okay to move forward.

## **2. Centre for clinical trials**

Natalie circulated the spreadsheet in early August that Antonino created which outlines the venues around the world that are able to host clinical trials. Natalie will resend the document when the minutes are sent out. We only heard back from Slovakia and Georgia who can both host clinical trails.

Carol-Anne mentioned that she participated in a meeting last week with Conect4Children.org who will help/share protocols for getting clinical trials going in various counties in Europe. The group is made up of pharmaceutical companies, hospitals, administrators, etc. It would be worth tapping into for future clinical trials and it's a really positive association. She will send the information to the group via Whatsapp.

## **3. International Registry**

Antonino presented with Majid on facebook about a month ago about the International Registry. He wonders if it is worth doing again for anyone who was unable to attend. Natalie suggested that they post it youtube so people can view it again rather than completing another presentation. Antonino agreed and suggested that they could prepare with subtitles in different languages and also add it to the alliance website.

Maria said that the feedback she has received is that until the registry is in Russian, people don't want to participate. Antonino explained that registry is open and many have registered and they are working on making it available in more languages.

Carol-Anne asks how many kids are registered so far. Antonino said that after the webinar there were about 100 kids registered at that time. Carol-Anne noted that because the registry isn't mobile friendly, they will likely lose a lot of families who don't have a laptop or desktop computer.

## **4. Open Discussion**

Patric said that they have decided to cancel the family conference for June 2021 due to COVID-19. They don't see how they are able to move forward with it right now. They discussed whether they would try and host it virtually but they need to find someone who has the skills to do that and they don't have that person. Rick acknowledged that it was much more work to do it virtually than IFCR expected this past June but offered that they could help Germany/Switzerland/Austria if they decided to move forward virtually. Antonino suggests we re-evaluate in January and see if the Covid situation has changed as he believes it is unlikely that a physical meeting will be possible in 2021. Virtually it is difficult when we are dealing with so many different time zones. There is lots of creative ways to do it virtually, without doing it live. Presentations could be pre-recorded and posted online. Between LouLou and IFCR we will have some good experience in virtual conferences because LouLou will be doing it in October.

## **Recap**

The partnership agreement will be reviewed and produced into manifesto that is not legally binding. We will resend the clinical trial spreadsheet for review and ask that countries get back to us with confirmation of sites. Antonino will address the registry concerns of not being mobile friendly and increasing the number of languages its presented in, and will relaunch the presentation of registry he hosted on facebook.

Katheryn, Peter (Slovakia), Natia (Georgia), Nazi joined late due to error with the time of the meeting and Antonino and Natalie will stay on the line and catch everyone up.

Katheryn's organization is willing to help support the cost of the Alliance website. Natalie will ask C-A to add Peter to whatsapp group chat.