

CDKL5 Alliance Manifesto

This manifesto outlines the guiding principles, organization, and operational guidelines of the CDKL5 Alliance. In joining the Alliance, Members signal their agreement with this manifesto.

RECITALS

☒ CDKL5 Deficiency Disorder (“CDD”) is a rare genetic disease that leads to frequent seizures shortly after birth and severe impairment in neurological development, with most affected people being unable to walk, talk or care for themselves.

☒ All Alliance Members have direct or indirect involvement with issues relating to the management of symptoms, treatments or general condition of people with CDD.

☒ The Members wish to jointly collaborate on shaping a more positive future for people with CDD around the world.

In consideration of the above, the Members (National Family Associations) agree as follows: The name of the organization shall be “CDKL5 Deficiency Disorders Alliance” or, in short, “CDKL5 Alliance”

PURPOSE

The Alliance is set up with the following aims:

☒ To improve growth of the international CDD community, building a stronger network among all the existing and future National Family Associations.

☒ To help develop, and then support, an active network of CDD specialists in order to help share knowledge and spread best practices;

☒ To support the goal of having all those living with CDD included in a national or international registry, duly authorised by the proper national or international authorities, where possible.

☒ To identify opportunities for lobbying, in order to raise the social, political and medical awareness of CDD

☒

PRINCIPLES OF BEHAVIOUR

Members agree to always perform their activities and behaviour according to the highest ethical standards and to abide by the following guiding principles in their interactions within the Alliance. These principles are designed to improve the Alliance’s effectiveness and credibility.

Openness and transparency

Openness and transparency are essential in all aspects of the Alliance’s operation and communication. This means that the Members should share information in a timely and accurate manner;

Sharing good and best practice

The Members recognise that each of them has something to give to the Alliance and, by the same token, all of them have something to get back from it. They will share learnings and best practices.

Commitment to flexibility

As participants in a new Alliance, all Members acknowledge that they have much to learn from each other and that there may be times when things do not go according to plan or to expectation. Flexibility and forbearance will be needed.

ORGANIZATION AND MANAGEMENT

4.1 The Partnership shall be governed by:

(a) The Meeting of the Partners; and

(b) The Leadership Board.

(c) The Chair

4.2 The Partnership shall also have two elected seats:

(a) The Chair

(b) The Secretary.

MEETING OF THE PARTNERS

5.1 The Meeting of the Partners is the principal authority of the Partnership.

5.2 The Meeting of the Partners has the non-transferable authority to make the following decisions:

(a) Change in the Objective of the Partnership;

(b) Defining the strategy and common goals;

(c) Appointment and removal of the Leadership Board;

(d) Admission of new Partners, exclusion of a Partner, acceptance of a Partner's withdrawal;

(e) Approval of the three-year plan of activities;

(f) New alliances; and

(g) Termination of the Partnership.

5.3 Each year there will be at least two main meetings of the Alliance.

☑ The first will be convened at the CDKL5 International Family Conference premises which rotates between Europe and North America each year (the Leadership Board may also consider including Asia and South America as potential hosts in the future). The attendees at this conference, in addition to the Members, are mainly families plus a number of researchers, pharmaceutical companies and public authorities. The attendance at these conferences continues to grow as families are looking for help with the daily needs of those living with CDD and are interested to learn about ongoing research and clinical trials to ultimately find a cure.

☑ The second Alliance meeting will take place at the LouLou Foundation's Scientific Forum. This event is currently by invite only for CDD clinical doctors, researchers, pharmaceutical companies, public health and regulatory authorities, and one representative from CDD National Family Association.

☑ In the event that either of those meetings does not take place in a given year, the Leadership Board may determine to hold the meeting as near as possible to the time when the CDKL5 International Family Conference or LouLou Foundation's Scientific Forum takes place, either electronically or, preferably, in person at a location of the Leadership Board's choosing.

ARTICLE 6 – LEADERSHIP BOARD

6.1 The management of the Partnership is entrusted to a

1. Leadership Board, composed by from 4 (four) to 7 members (seven)

2. The chairperson of the Leadership Board shall be the Chair.

3. The Secretary

All chosen among the members of all the National Family Associations and elected for 3 years at a Meeting of the Members.

Each member of the Leadership Board will serve as representative of a number of National Family

Associations to keep the full organization live and engaged.

6.1 The Leadership Board will elect the Chairman and Secretary.

6.2 The Leadership Board is responsible for all activities necessary for the operation of the Partnership, provided that these activities are not reserved to the Meeting of the Partners.
Activities

necessary for the operation of the Partnership will include:

- (a) Representation of the Partnership to third parties;
- (b) Preparation of a three-year plan of activities;
- (c) Planning and coordination of the projects;
- (d) Lobbying and communications;
- (e) Appointment of the Chair and of the Secretary;
- (f) Execution of the Members Meeting decisions;

6.4 Meetings of the Leadership Board will be organized on a bi-monthly basis via video call or conference call using Zoom or another available platform.

6.5 The Leadership Board shall meet as often as required by the affairs of the Partnership, or at the request of one of the members.

6.6 The Leadership Board may take decisions only if $\frac{3}{4}$ of all members attend in person or electronically.

With the consent of the majority of the Leadership Board, decisions may validly be taken by exchange of electronic mail.

The members of the Leadership Board may attend the meetings by electronic means, including telephone and video-conferencing, provided precautions are taken to ensure continued communication throughout the meeting.

6.7 Decisions of the Leadership Board must pass by a majority of all members, including those not in attendance.

6.9 The chairperson of the Leadership Board shall be the Chair, who shall not have a second or casting vote.

6.10 Minutes shall be taken of the meetings of the Leadership Board. The Secretary will take care of drafting the minutes and send them to the Leadership Board members for their approval within two weeks of the meeting date. They must record the decisions made.

ARTICLE 7- ELECTED POSITIONS: CHAIR AND SECRETARY

7.1 The Chair

(a) The Chair will be appointed among the Leadership members by a majority vote of the Leadership Board members.

(b) The Chair shall be part of the Leadership Board and shall serve in its position for the same 3 year duration of the Leadership Board.

(c) The Chair shall co-ordinate the activities of the Leadership Board and shall have the responsibility to submit to the approval of the Partners Meeting any topic that need to be approved by such meeting.

7.2 The Secretary

(a) The Secretary will be appointed by the Leadership Board by a majority vote of its members.

In selecting the Secretary, the Leadership Board shall take into account any candidate proposed by the Partners or any other voluntary candidate.

(b) The Secretary shall serve in its position for the same 3 year duration of the Leadership Board.

(c) The Secretary shall be on charge of:

(i) organizing (call, seat, timing) any meeting of the Members and preparing minutes of

such meetings;

(ii) organizing (call, seat, timing) any meeting of the Leadership Board and preparing minutes of such meetings;

(iii) other responsibilities as mutually agreed by the Secretary and the Chair and approved by the Leadership Board;

New Members

12.1 The admission of a new Member into the Alliance requires the approval of 67% of Members.

Admission is (unless otherwise agreed by all Members) subject to the new Member's unconditional agreement in writing to all the terms of the present Agreement and is also conditional upon the new Member having direct or indirect involvement with issues relating to the CDD.

12.1.3 In order to be permitted to join the Alliance as a Member, an organisation must meet one of these requirements:

Be an officially registered, in his Country, non-profit organisation wholly devoted to those affected by CDD. An organization that is international in nature but serves as the primary family organization for its home country--the International Foundation for CDKL5 Research (IFCR), for example--fulfills this requirement. This Organisation will have voting rights

Be an officially registered Private Foundation wholly devoted to those affected by CDD. This Organization will have no voting rights

For the Countries where is forbidden or very difficult to register a non -profit organisation the

Partner can be admitted with a written formal request to be part of the CDKL5 Alliance. The formal request has to be signed by at least 5 Families. This kind of Partner will actively participate to the CDKL5 Alliance life excluding any occasion when a vote has to be cast for any reasons

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